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Revisiting the Legal Standards that Govern Requests to Sterilize Profoundly Incompetent Children: In Light of the "Ashley Treatment," is a New Standard Appropriate?

Cover Page Footnote

J.D. Candidate, 2009, Fordham University School of Law. I would like to thank my parents for their constant love and support and for always encouraging me to achieve my goals.

REVISITING THE LEGAL STANDARDS THAT GOVERN REQUESTS TO STERILIZE PROFOUNDLY INCOMPETENT CHILDREN: IN LIGHT OF THE “ASHLEY TREATMENT,” IS A NEW STANDARD APPROPRIATE?

Christine Ryan*

This Note discusses the recent controversy surrounding a six-year-old girl named Ashley, whose parents chose to purposefully stunt her growth and remove her reproductive organs for nonmedical reasons. A federal investigation determined that Ashley's rights had been violated because doctors performed the procedure, now referred to as the “Ashley Treatment,” without first obtaining a court order. However, the investigation did not make any conclusions regarding whether the “Ashley Treatment” could present a legally permissible treatment option in the future. After discussing the constitutional rights that the “Ashley Treatment” implicates and the current legal standards in place, this Note examines how courts have applied these legal standards to cases involving extreme requests. Drawing upon legal commentators, this Note concludes that a court could approve a request for the “Ashley Treatment” in appropriate and limited cases where the parents have presented clear and convincing evidence before a court that the benefits that the “Ashley Treatment” would provide to the child and her family outweigh the risks associated with the procedure. This Note argues that those benefits may include extrinsic considerations, but courts should remain cautious when considering such evidence and be sure that the evidence as a whole supports their conclusions.

INTRODUCTION

The most humane way you can treat somebody is to treat them appropriately for what their needs are and what their context is. You don't treat everybody identically. You treat them as a person, which means they are different from the person sitting next to them.

What treating Ashley humanely means is recognizing what her world is and will be for a long time is her loving family, her parents. That is

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where she gets her love. That is where she gets her care. It's a small world. And what these parents requested are three things they feel will make her life better in that small world. I think that's treating her humanely.¹

In an interview with Larry King on January 12, 2007, Dr. Douglas S. Diekema defended his involvement in an ethical and moral debate surrounding a nine-year-old girl from Seattle, known only as Ashley. The controversy arose in October 2006 after Dr. Diekema and his colleague, Dr. Daniel F. Gunther, published an article called *Attenuating Growth in Children with Profound Developmental Disability*.² The article advocated growth attenuation and hysterectomy for a profoundly incompetent³ and nonambulatory six-year-old girl,⁴ later identified by her parents as Ashley.⁵ The stated purpose of the treatment plan was to improve Ashley's quality of life and to help her parents prolong home care.⁶ Immediately following the publication of the article in October 2006, members of the medical and disability communities reacted strongly to Diekema and Gunther's proposal.⁷ The American Association on Intellectual and Developmental Disabilities⁸ publicly condemned Gunther and Diekema for suggesting that growth attenuation therapy could justifiably be performed on children with

1. Telephone Interview by Larry King with Dr. Douglas S. Diekema, Dir. of Educ., Truman Katz Ctr. for Pediatric Bioethics at Seattle Children's Hosp., in Seattle, Wash. (Jan. 12, 2007).

2. Daniel F. Gunther & Douglas S. Diekema, *Attenuating Growth in Children with Profound Developmental Disability: A New Approach to an Old Dilemma*, 160 ARCHIVES PEDIATRIC ADOLESCENT MED. 1013 (2006).

3. This Note focuses on "profoundly incompetent" children, which are those children that possess the lowest possible level of competency. Typically, profoundly incompetent individuals are described as having an I.Q. below twenty. See *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 442 n.9 (1985); see also Norman L. Cantor, *The Bane of Surrogate Decision-Making: Defining the Best Interests of Never-Competent Persons*, 26 J. LEGAL MED. 155, 158 (2005) ("Profoundly disabled persons, by definition, have never had the capacity for autonomy. They have never had the ability to issue instructions . . . or to form values and preferences that would guide surrogate decision-makers."). Other levels of competency, as measured by I.Q., that are outside the scope of this Note are mild (50–55 to 70), moderate (35–40 to 50–55), and severe (20–25 to 35–40). AM. PSYCHIATRIC ASS'N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 49 (4th ed., rev. 2000).

4. Gunther & Diekema, *supra* note 2, at 1014.

5. The "Ashley Treatment," <http://ashleytreatment.spaces.live.com/blog> (Jan. 2, 2007).

6. Gunther & Diekema, *supra* note 2, at 1014.

7. See, e.g., Ethan B. Ellis, *Disabling Children With Disabilities*, 161 ARCHIVES PEDIATRIC ADOLESCENT MED. 419, 419 (2007) ("[I]ntense anger . . . was my first reaction and the universal reaction of my colleagues in the disability movement."); see also Hank Bersani, *Growth Attenuation: Unjustifiable Non-Therapy*, 161 ARCHIVES PEDIATRIC ADOLESCENT MED. 520 (2007); Carole L. Marcus, *Only Half the Story*, 161 ARCHIVES PEDIATRIC ADOLESCENT MED. 616 (2007). For a summary of the specific critiques of several disability organizations, see Kristi L. Kirschner et al., *Ashley X*, 86 AM. J. PHYSICAL MED. & REHABILITATION 1023, 1027, 1029 & nn.28–31 (2007).

8. The mission of the American Association of Intellectual and Developmental Disabilities is to "promote[] progressive policies, sound research, effective practices and universal human rights for people with intellectual and developmental disabilities." Am. Ass'n on Intellectual & Developmental Disabilities, Mission Statement, http://www.aaidd.org/About_AAIDD/mission_statement.shtml (last visited Sept. 20, 2008).

mental disabilities.⁹ However, many of the reactions from the public were fueled by emotion, rather than fact.¹⁰ Ashley's parents, dissatisfied with the way the media had portrayed their family's story, decided to come forward to respond. They launched a blog on January 2, 2007, in order to correct misconceptions surrounding the treatment plan and their motives, as well as to help similarly situated families obtain more information about the treatment.¹¹ The blog provoked considerable response from the public; Ashley's parents received more than three thousand e-mail messages in ten days.¹² Despite the initial number of critics of the "Ashley Treatment," an overwhelming majority of the people who visited the blog was supportive of Ashley's parents' choice.¹³

Nonetheless, the story continued to recruit critics.¹⁴ Activists from Feminist Response in Disability Activism demanded that the American Medical Association publicly renounce the procedure¹⁵ and called for state

9. Am. Ass'n on Intellectual & Developmental Disabilities, Board Position Statement: Growth Attenuation Issue, <http://www.aamr.org/Policies/growth.shtml> (last visited Sept. 20, 2008).

10. See Daniel F. Gunther & Douglas S. Diekema, *Disabling Children with Disabilities—In Reply*, 161 ARCHIVES PEDIATRIC ADOLESCENT MED. 419, 420 (2007) (commenting that the "initial visceral reaction is often fueled, at least in part, by some misunderstandings and a failure to appreciate some important distinctions we set out in our article").

11. The "Ashley Treatment," <http://ashleytreatment.spaces.live.com/blog> (Jan. 9, 2007) ("Upon reviewing some press and TV coverage, we wish the media would be more careful in reading our story and more precise in interpreting and reporting it. We've seen many instances of sensationalist spin and misinterpretation."). For an example of a misperception that circulated, see Benjamin S. Wilfond, *The Ashley Case: The Public Response and Policy Implications*, HASTINGS CENTER REP., Sept.–Oct. 2007, at 12, 12, which describes how some discussions had associated the growth attenuation therapy performed on Ashley with hypodermic needles and bone fusion, creating the misleading idea that she had been "frozen."

12. When asked on January 12, 2007, about the public's response to their blog, Ashley's parents responded: "We have received 3,600 plus private messages. They continue to flow at the rate of 200 a day." Telephone Interview by Larry King with Dr. Douglas Diekema, *supra* note 1. As of December 31, 2007, Ashley's parents had received a total of 4705 e-mail messages. The "Ashley Treatment," <http://ashleytreatment.spaces.live.com/blog> (Dec. 31, 2007).

13. Telephone Interview by Larry King with Dr. Douglas Diekema, *supra* note 1. As of December 31, 2007, of the 3903 e-mail messages received that took a position on the "Ashley Treatment," 93.9% supported the "Ashley Treatment" (3665), while only 6.1% disapproved (238). The "Ashley Treatment," <http://ashleytreatment.spaces.live.com/blog> (Dec. 31, 2007).

14. Gerald D. Coleman, *The Irreversible Disabling of a Child: The "Ashley Treatment,"* 7 NAT'L CATH. BIOETHICS CENTER 711, 718–20 (2007); see also Alicia R. Ouellette, Growth Attenuation, Parental Choice, and the Rights of Disabled Children: Lessons from the Ashley X Case 11–15 (Jan. 1, 2008) (unpublished working paper), available at <http://ssrn.com/abstract=1084903>.

15. Coleman, *supra* note 14, at 719. After meeting with several activists about its apparent endorsement of the "Ashley Treatment," the American Medical Association (AMA) clarified its position to Feminist Response in Disability Activism on March 5, 2007: "The AMA currently has no official policy on the treatments outlined in [Dr. Gunther and Dr. Diekema's] article." Feminist Response in Disability Activism, <http://fridanow.blogspot.com/2007/03/yes-we-got-letter-from-dr.html> (Mar. 19, 2007, 08:06 EST).

and federal officials to investigate whether Ashley's rights had been violated. The Washington Protection and Advocacy System (WPAS),¹⁶ a federally mandated watchdog organization, commenced an investigation on January 6, 2007, to determine precisely what had happened to Ashley.¹⁷ The WPAS published its findings in an investigative report that presented a compilation of the details of Ashley's condition and her parents' decision to proceed with surgical intervention.¹⁸ The remainder of this Introduction describes Ashley's story leading up to the publication of the investigative report, and her situation currently.

Shortly after birth, Ashley began demonstrating physical and mental signs of abnormal cognitive development.¹⁹ Doctors performed several tests and determined that Ashley's brain had stopped developing, leaving her with the mental capacity of a six-month-old baby.²⁰ Ashley's I.Q. is so low that it is untestable,²¹ classifying her as profoundly disabled.²² Doctors eventually diagnosed Ashley's condition as static encephalopathy of unknown origin.²³ In lay terms, static encephalopathy means brain damage that is unlikely to improve over time.²⁴ In Ashley's case, the likelihood that her condition will improve is virtually nonexistent.²⁵

As a result of her disease, Ashley is completely dependent on others.²⁶ She is incapable of sitting up on her own, holding her head up, or changing

16. Washington Protection and Advocacy System, <http://www.wpas-rights.org/index.htm> (last visited Sept. 20, 2008). As of June 1, 2007, the Washington Protection and Advocacy System (WPAS) changed its name to Disability Rights Washington. See Disability Rights Washington, <http://www.disabilityrightswa.org/> (last visited Aug. 27, 2008).

17. DAVID R. CARLSON & DEBORAH A. DORFMAN, WASH. PROT. & ADVOCACY SYS., INVESTIGATIVE REPORT REGARDING THE "ASHLEY TREATMENT," (2007) [hereinafter WPAS INVESTIGATIVE REPORT], available at <http://www.disabilityrightswa.org/news-1/Investigative%20Report%20Regarding%20the%20Ashley%20Treatment.pdf>. WPAS has federal authority pursuant to the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15041 (2000), the Protection and Advocacy for Mentally Ill Individuals Act, *Id.* § 10801, and the Protection and Advocacy of Individual Rights Act, 29 U.S.C. § 794(e) (2000). WPAS INVESTIGATIVE REPORT, *supra*, at 5.

18. See generally WPAS INVESTIGATIVE REPORT, *supra* note 17.

19. See Gunther & Diekema, *supra* note 2, at 1014 (indicating that Ashley displayed symptoms of diminished muscle tone, feeding difficulty, involuntary bodily movements, and developmental delay).

20. WPAS INVESTIGATIVE REPORT, *supra* note 17, at 11 n.32.

21. Letter from Larry A. Jones, Law Offices of Larry A. Jones, to Ashley's Dad 2 (June 10, 2004), available at http://www.disabilityrightswa.org/news-1/Investigative%20Report%20Regarding%20the%20Ashley%20Treatment_Exhibits%20-%20-%20T.pdf (appended to WPAS's investigative report as Exhibit O).

22. See *supra* note 3.

23. See Ashley's Mom and Dad, The "Ashley Treatment," Towards a Better Quality of Life for "Pillow Angels"© 1 [hereinafter Pillow Angels], available at <http://pillowangel.org/Ashley%20Treatment%20v7.pdf>.

24. See STEDMAN'S MEDICAL DICTIONARY (27th ed. 2000) (defining encephalopathy as any disorder of the brain).

25. See Gunther & Diekema, *supra* note 2, at 1014.

26. Pillow Angels, *supra* note 23, at 1.

her sleeping position.²⁷ Ashley cannot use language, and she is fed through a gastrostomy tube.²⁸ She cannot hold a toy on her own.²⁹ She rarely makes eye contact, and her parents are not even sure if she recognizes them.³⁰

Nonetheless, Ashley is conscious and interactive. She is able to move her arms and kick her legs.³¹ She displays no physical deformities.³² She will often “smile[] and express[] delight” when others are around, or when music is playing.³³ During the week, she attends school with other special-needs children, where she participates in daily activities and bus trips.³⁴

In early 2004, at age six, Ashley manifested signs of precocious adolescence and accelerated growth.³⁵ Her parents became concerned that continued home care would not be feasible.³⁶ Ashley’s parents took their concerns to Doctors Gunther and Diekema at Seattle Children’s Hospital. Together, they developed a novel medical procedure that came to be known as the “Ashley Treatment.”³⁷

The decision to proceed with this novel treatment was not automatic. Ashley’s parents first presented the proposal in May 2004 to Seattle Children’s Hospital’s forty-person ethics committee.³⁸ The committee evaluated Ashley’s medical condition, her parent’s motivation for seeking the intervention, and whether the procedure would improve her quality of

27. *Id.*

28. Gunther & Diekema, *supra* note 2, at 1014.

29. Pillow Angels, *supra* note 23, at 1.

30. *Id.* at 1, 3.

31. *Id.* at 1.

32. *Id.* at 1–2.

33. *Id.* at 1, 3. According to her parents, Ashley’s favorite musician is Andrea Bocelli. *Id.* at 1.

34. *Id.*

35. See Gunther & Diekema, *supra* note 2, at 1014 (indicating that Ashley moved from the 50th percentile to the 75th percentile for length in under six months).

36. *Id.*

37. The “Ashley Treatment,” <http://ashleytreatment.spaces.live.com/blog> (January 12, 2007, 07:56 EST) (“The Ashley Treatment is the name we have given to a collection of medical procedures for the improvement of Ashley’s quality of life.”); see *infra* text accompanying notes 51–58 (providing a complete description of the procedure); see also The “Ashley Treatment” for the wellbeing of “Pillow Angels,” <http://pillowangel.org/AT%20Summary.jpg> (last visited Sept. 20, 2008) (offering a pictorial summary of the treatment and its benefits). Also of note, Dr. Douglas Diekema had already considered the problem that families like Ashley’s face. Less than one year before Ashley’s parents visited Seattle Children’s Hospital, Dr. Diekema published an article that suggested a new way to view surrogate decision making in the sterilization context. Ironically, many of the factors in his article that he insisted were necessary were not present in Ashley’s case. See Douglas S. Diekema, *Involuntary Sterilization of Persons with Mental Retardation: An Ethical Analysis*, 9 MENTAL RETARDATION & DEVELOPMENTAL DISABILITIES RES. REV. 21, 25 (2003) (insisting that sterilization be performed only when it was “urgently necessary,” and never before pubescence).

38. See ETHICS COMM., CHILDREN’S HOSP. & REG’L MED. CTR., SPECIAL CHRMC ETHICS COMMITTEE MEETING/CONSULTATION (May 5, 2004) [hereinafter CHRMC ETHICS COMMITTEE], available at http://www.disabilityrightswa.org/news-1/Investigative%20Report%20Regarding%20the%20Ashley%20Treatment_Exhibits%20K%20-%20T.pdf (appended to WPAS’s investigative report as Exhibit L).

life.³⁹ The committee performed a balancing test to determine whether the prospective benefits outweighed potential harms and risks.⁴⁰ In sum, the risks of the procedure included increased likelihood of deep vein thrombosis, possible weight gain and nausea, and surgical risks and recovery discomfort.⁴¹ The benefits of the procedures were facilitating home care, improving Ashley's quality of life and comfort, and avoiding the physical, emotional, and hygienic problems associated with menstruation.⁴² The committee unanimously concluded that the "Ashley Treatment" was appropriate under the circumstances.⁴³ Nonetheless, the committee advised the parents to seek legal advice so they could satisfy the legal standards governing sterilization required under Washington state law.⁴⁴

Ashley's parents took the committee's advice and sought the legal services of Larry A. Jones, a Seattle lawyer familiar with disability law.⁴⁵ In June 2004, after reviewing applicable case law, Jones advised Ashley's parents that the treatment could go forward without a court order.⁴⁶ He distinguished prior case law as inapplicable to Ashley's case and ultimately concluded that Washington state law "must be read to allow sterilization when it is merely a byproduct of surgery performed for other compelling medical reasons."⁴⁷ He based this conclusion on the severity of Ashley's incompetence and the permanence of her condition.⁴⁸ Jones concluded that the procedures would make permanent home care an attainable reality for Ashley and her parents, which was a "medically necessary benefit" that was "compelling."⁴⁹ Doctors performed the "Ashley Treatment" on Ashley one month later in July 2004.⁵⁰

The "Ashley Treatment" is a combination of three medical procedures having the stated purpose of improving the quality of life and well-being of a profoundly incompetent child.⁵¹ First, doctors administered high doses of estrogen to reduce Ashley's final height and overall weight.⁵² The principal

39. *Id.*

40. *See id.* at 2–3.

41. *Id.*

42. *Id.*

43. *Id.* at 3; *see also* Telephone Interview by Larry King with Dr. Douglas Diekema, *supra* note 1 ("I can tell you that there was no one in the room who disagreed with the decision.").

44. *See* CHPMC ETHICS COMMITTEE, *supra* note 38, at 3.

45. *See* Law Offices of Larry A. Jones, <http://www.seattledisabilitylaw.com/welcome.html> (last visited Sept. 20, 2008) (describing Larry A. Jones's background and experience with disability cases).

46. Letter from Larry A. Jones to Ashley's Dad, *supra* note 21, at 4.

47. *Id.*

48. *Id.* at 2–4.

49. *Id.* at 1, 4.

50. Pillow Angels, *supra* note 23, at 6.

51. *See id.* at 4–5.

52. *See id.* at 6 (estimating that treatment, which took two and a half years to complete, will reduce Ashley's projected height by 20%, and projected weight by 40%). On December 31, 2007, Ashley's parents provided an update: "Ashley today weighs 63 pounds and is 53

benefit of attenuating growth was to permit others to move Ashley more easily, consequently increasing her participation in family activities.⁵³ Ashley's parents were also motivated by their desire to continue caring for her in their home.⁵⁴ Second, doctors removed Ashley's breast buds to prevent breast development.⁵⁵ This was intended to reduce Ashley's discomfort when recumbent or fastened into her wheel chair.⁵⁶ The breast bud removal was preventative in nature as well. According to Ashley's parents, reducing breast size would avert breast cancer and fibrocystic growths—which both ran in Ashley's family—and would prevent the possibility that Ashley's breasts would sexualize her to a caregiver.⁵⁷ Lastly, doctors removed Ashley's uterus to prevent menstruation and the physical discomfort menstruation would cause her.⁵⁸

After reviewing state law that focused on the sterilization of incompetent children, the WPAS investigative report concluded that performing the "Ashley Treatment" without a court order violated Ashley's constitutional due process rights, common-law rights, and Washington state law.⁵⁹ The WPAS developed several corrective actions for the hospital to implement to prevent performing any procedure involving sterilization on a minor without first obtaining a court order.⁶⁰ Despite its harsh critique of the hospital's protocol, the WPAS investigative report issued no opinion on how the court would have ruled on the "Ashley Treatment" in Ashley's specific case or whether any state court will ever authorize a similar procedure in the future.⁶¹

This Note will examine whether the current legal standards governing surrogate decision making for the profoundly disabled are adequate to

inches (4' 5") tall, unchanged from a year ago" The "Ashley Treatment," <http://ashleytreatment.spaces.live.com/blog> (Dec. 31, 2007).

53. Pillow Angels, *supra* note 23, at 7 ("The main benefit of the height and weight reduction is that Ashley can be moved considerably more often, which is extremely beneficial to her health and well being. . . . As a result, Ashley can continue to delight in being held in our arms and will be moved and taken on trips more frequently and will have more exposure to activities and social gatherings . . . instead of lying down in her bed staring at TV (or the ceiling) all day long.").

54. *See id.*

55. *See id.* at 9 (stressing that performing the breast bud procedure in a young girl is simpler than performing a mastectomy on an adult woman with fully formed breasts). *But see* Gunther & Diekema, *supra* note 2 (omitting discussion of the removal of breast buds).

56. *See* Pillow Angels, *supra* note 23, at 9.

57. *See id.*

58. *See id.* at 8 (asserting incidental benefits of removing Ashley's uterus included a reduced possibility of pregnancy and uterine cancer). *But see* WPAS INVESTIGATIVE REPORT, *supra* note 17, at 11–12 (suggesting that the prevention of pregnancy appears to be one of the main purposes, rather than merely an additional benefit).

59. WPAS INVESTIGATIVE REPORT, *supra* note 17, at 1, 27.

60. *See id.* at 2–4.

61. *Id.* at 28. According to Georgia State University law professor Paul Lombardo, Washington state law presents one of the highest burdens for petitioners seeking sterilization. *See Removal of Girl's Uterus in 'Ashley Treatment' Breaks State Law*, WIRED.COM, May 8, 2007, http://www.wired.com/medtech/health/news/2007/05/ashley_legal#corrections.

address whether parents or guardians may request that the "Ashley Treatment" be performed on their child. Currently, questions of surrogate decision making are analyzed using some form of a substituted judgment analysis⁶² or a best interests test.⁶³ As this Note demonstrates, the application of these standards changes depending on the particular facts of a case and the evidence available.⁶⁴ Courts employ the substituted judgment analysis when the person articulated a clear preference while previously competent.⁶⁵ Courts use the best interests test when the person did not articulate a clear preference or has been incompetent since birth.⁶⁶ This Note argues that, because the "Ashley Treatment" infringes on both fundamental rights and interests, parents requesting this treatment must present clear and convincing evidence that justifies the infringement. Courts may assess a number of considerations, not merely medical in nature. This Note asserts that extrinsic considerations, such as psychological welfare, emotional effect, social benefit, and effect on the familial structure are all important considerations. This Note argues that, if the parents present evidence that the infringement of fundamental rights is clearly outweighed by the benefit of the treatment, then the "Ashley Treatment" may provide a legally permissible treatment option in such a limited circumstance.

Part I discusses the constitutional rights that the "Ashley Treatment" implicates and the legal standards courts have applied in situations where parents or guardians request sterilization for their profoundly incompetent child. Part II describes how courts have applied these standards unpredictably based on the facts, creating confusing jurisprudence. Part III.A first evaluates the case law described in Part II and takes the position that a strict application of the legal standards is not helpful as applied to the "Ashley Treatment." Part III.B proposes that courts examine the "Ashley Treatment" in light of several considerations, such as medical, social, psychological, and familial benefit. This Note concludes by describing how this approach will permit courts to approve of the "Ashley Treatment" in appropriate and limited situations.

I. THE CONSTITUTION, INDIVIDUAL RIGHTS, AND THE PROTECTION OF THOSE RIGHTS THROUGH APPROPRIATE LEGAL STANDARDS

Part I discusses the current constitutional and legal framework to which the "Ashley Treatment" must conform. The U.S. Constitution enumerates explicit rights belonging to the people.⁶⁷ The U.S. Supreme Court has also recognized additional rights that the founding fathers did not explicitly

62. See *infra* Part I.B.1.

63. See *infra* Part I.B.2.

64. See generally *infra* Part II.

65. See *infra* text accompanying notes 138–50.

66. See *infra* text accompanying notes 156–85.

67. See, e.g., U.S. CONST. amends. I, II, IV, VI, VII.

articulate, but that the Bill of Rights nonetheless protects.⁶⁸ As these individual rights became more apparent, courts began to invalidate state intervention that infringed on these fundamental rights.⁶⁹ Individual rights, the Supreme Court declared, must be protected against abuses of power that threaten to terminate or truncate those rights.⁷⁰

The “Ashley Treatment” implicates two important categories of individual rights: (1) the profoundly incompetent child’s rights, and (2) his or her parents’ right to control and direct their child’s upbringing. Part I.A describes and outlines the rights of these two classes of individuals as the Constitution protects them today. Part I.B then describes the legal standards that courts have developed to ensure a delicate balance between the protection of the child’s rights and the infringement upon her parents’ rights within the context of sterilization.

A. Constitutional Guarantees of Individual Rights

This section describes the constitutional rights of parents and children within the context of sterilization requests. Part I.A.1 introduces two conflicting definitions of personhood. Parts I.A.2 and I.A.3 indicate how the Court has provided incompetent children with the same rights as competent children, specifically the right to be left alone and the right to procreate. Finally, Part I.A.4 describes how parents are limited in their ability to infringe upon these protected constitutional rights but nonetheless retain some ability to control their children’s upbringing.

1. The Rights of Profoundly Incompetent Children

The Constitution provides that no state shall “deprive any person of life, liberty, or property, without due process of law.”⁷¹ Who qualifies as a “person” has generated much debate, especially in the context of the

68. *Griswold v. Connecticut*, 381 U.S. 479, 484, 486 (1965) (respecting marital privacy); *see, e.g., Lawrence v. Texas*, 539 U.S. 558 (2003) (holding that a ban on homosexual sodomy was an unconstitutional infringement of the right of sexual liberty); *Carey v. Population Servs. Int’l*, 431 U.S. 678 (1977) (protecting the right of minors to obtain contraception); *Roe v. Wade*, 410 U.S. 113, 155 (1973) (recognizing the right to obtain an abortion); *Eisenstadt v. Baird*, 405 U.S. 438 (1972) (respecting the private choices of unmarried couples); *Loving v. Virginia*, 388 U.S. 1, 12 (1967) (classifying the right to marry as a “fundamental” right).

69. *See, e.g., Lawrence*, 539 U.S. at 585; *Stenberg v. Carhart*, 530 U.S. 914, 945–46 (2000); *City of Akron v. Akron Ctr. for Reprod. Health*, 462 U.S. 416, 442 (1983); *Eisenstadt*, 405 U.S. at 447; *Skinner v. Oklahoma ex. rel. Williamson*, 316 U.S. 535, 541 (1942) (invalidating a statute authorizing the sterilization of criminals because it denied them the constitutionally protected rights of procreation and marriage); *Goodridge v. Dep’t of Pub. Health*, 798 N.E.2d 941 (Mass. 2003).

70. *See Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833, 898 (1992) (“The Constitution protects all individuals, male or female, married or unmarried, from the abuse of governmental power . . .”).

71. U.S. CONST. amend XIV, § 1.

profoundly disabled.⁷² Persons are entitled to full moral rights and legal status, while nonpersons are not.⁷³

Depending on the definition of personhood, some profoundly incompetent individuals may not exhibit the necessary characteristics. Under one view, the status of profoundly disabled individuals is uncertain because this definition of personhood requires a minimum level of intellectual functioning.⁷⁴ Intellectual functioning requires both internal thinking and external action.⁷⁵ This may include the ability to make life plans, communicate, form human relationships, comprehend moral principles, recognize one's personal identity over time, or perceive one's experiences over time.⁷⁶ Some profoundly incompetent individuals, such as those in permanent comas, likely will be excluded under this definition of personhood.

A more inclusive definition of personhood encompasses profoundly incompetent individuals.⁷⁷ Society and the Supreme Court have recognized that moral status is applicable to all live human beings.⁷⁸ The United Nations Convention on the Rights of Persons with Disabilities provides that all disabled children have the same rights as nondisabled children.⁷⁹ Under this view, constitutional protections attach as soon as a person is born.⁸⁰ This definition recognizes consciousness as the minimum requirement of personhood.⁸¹ As such, this view may exclude those individuals—incompetent or not—who are in a permanent vegetative state or coma.⁸²

2. The Right to Be Left Alone

The Fourth Amendment provides, "The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and

72. See NORMAN L. CANTOR, MAKING MEDICAL DECISIONS FOR THE PROFOUNDLY MENTALLY DISABLED 17–19 (Glenn McGee & Arthur Caplan eds., 2005).

73. *Id.* at 13, 20.

74. *Id.* at 17–18.

75. MARY ANNE WARREN, MORAL STATUS: OBLIGATIONS TO PERSONS AND OTHER LIVING THINGS 90–95 (1997); see MICHAEL FREEDEN, RIGHTS 58–59 (Frank Parkin ed., 1991).

76. CANTOR, *supra* note 72, at 17–18.

77. *Id.* at 18.

78. *Roe v. Wade*, 410 U.S. 113, 157–58 (1973) ("[T]he word 'person,' as used in the Fourteenth Amendment, does not include the unborn."); CANTOR, *supra* note 72, at 20 (describing society's view).

79. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, art. 7, U.N. Doc. A/Res/61/106 (Dec. 13, 2006), available at <http://www.un.org/disabilities/convention/conventionfull.shtml#top>.

80. *Roe*, 410 U.S. at 158.

81. See John A. Robertson, *Assessing Quality of Life: A Response to Professor Kamisar*, 25 GA. L. REV. 1243, 1247 n.10 (1991). But see Edmund D. Pellegrino, *Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-Patient Relationship*, 10 J. CONTEMP. HEALTH L. & POL'Y 47, 49 (1994) ("Human beings who lack or have lost the capacity for autonomous actions are nonetheless humans who retain their inherent dignity.").

82. Robertson, *supra* note 81, at 1247.

seizures, shall not be violated”⁸³ In *Poe v. Ullman*, Justice John Marshall Harlan in dissent interpreted this amendment liberally, extending this protection to guard “the privacy of the home against all unreasonable intrusion of whatever character.”⁸⁴ This included protecting nonmaterial considerations, such as emotions, beliefs, and sensations:

The protection guaranteed by the [Fourth and Fifth] Amendments is much broader in scope. The makers of our Constitution undertook to secure conditions favorable to the pursuit of happiness. They recognized the significance of man’s spiritual nature, of his feelings and of his intellect. They knew that only a part of the pain, pleasure and satisfactions of life are to be found in material things. They sought to protect Americans in their beliefs, their thoughts, their emotions and their sensations. They conferred, as against the Government, the right to be let alone—the most comprehensive of rights and the right most valued by civilized men. To protect that right, every unjustifiable intrusion by the Government upon the privacy of the individual, whatever the means employed, must be deemed a violation of the Fourth Amendment.⁸⁵

The individual right to privacy and bodily integrity has limits, and must be weighed against the interests of society. In *Breithaupt v. Abram*, the Supreme Court held that the results of a blood test were admissible to prove intoxication, despite having been procured involuntarily while the accused was unconscious.⁸⁶ The interests of society in assessing intoxication, “one of the great causes of the mortal hazards of the road,” weighed in favor of admitting the evidence because the bodily intrusion was slight.⁸⁷

The interests of society have limits as well. No state may justify an invasive medical procedure to assist third parties when it is against the wishes of the individual.⁸⁸ To do so would violate the Fourth Amendment⁸⁹ as well as the Due Process Clause.⁹⁰

3. The Right to Procreate

In 1942, the Supreme Court recognized that the right to procreate is a fundamental right.⁹¹ While the Constitution does not explicitly enumerate the right to procreate, this right draws strength from several Bill of Rights

83. U.S. CONST. amend IV.

84. *Poe v. Ullman*, 367 U.S. 497, 550 (1961) (Harlan, J., dissenting).

85. *Olmstead v. United States*, 277 U.S. 438, 478 (1928) (Brandeis, J., dissenting) (alteration in original).

86. *Breithaupt v. Abram*, 352 U.S. 432, 439–40 (1957).

87. *Id.* at 439.

88. *Cruzan v. Mo. Dep’t of Health*, 497 U.S. 261, 313 n.13 (1990) (Brennan, J., dissenting).

89. *Winston v. Lee*, 470 U.S. 753, 759 (1985); *Schmerber v. California*, 384 U.S. 757, 772 (1966); see also *Washington v. Harper*, 494 U.S. 210, 221–22 (1990).

90. *Cruzan*, 497 U.S. at 287–88 (O’Connor, J., concurring) (“Illegally breaking into the privacy of the petitioner, the struggle to open his mouth and remove what was there, [and] the forcible extraction of his stomach’s contents . . . is bound to offend even hardened sensibilities.” (quoting *Rochin v. California*, 342 U.S. 165, 172 (1952))).

91. *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942).

amendments⁹² and the Fourteenth Amendment's Equal Protection⁹³ and Due Process⁹⁴ Clauses, and the case law that has developed reflects this.⁹⁵ These protections are guaranteed to all individuals, regardless of marital status,⁹⁶ and the courts have taken tremendous strides to ensure equal protection. For example, a child has the right to make autonomous reproductive decisions—such as, to seek an abortion—even if her parents object.⁹⁷ The Supreme Court overturned a state sterilization statute because it unconstitutionally required third-time criminal offenders to submit to compulsory sterilization.⁹⁸ Despite these advances, courts have struggled to apply the law evenhandedly to members of the mentally disabled community.⁹⁹ For the mentally incompetent, the right to procreate is often regarded as a fundamental, but dubious and uncertain right.¹⁰⁰

The law today is uncertain partly due to the Supreme Court's failure to overturn the infamous case of *Buck v. Bell*.¹⁰¹ Carrie Buck was an eighteen-year-old mentally incompetent girl challenging the validity of a Virginia statute that permitted "the sterilization of mental defectives."¹⁰² The opinion indicated that both Carrie's mother and Carrie's illegitimate child were mentally incompetent.¹⁰³ The rationale behind the statute was to promote "the welfare of society" by preventing incompetent individuals from passing on their genetic impairments to future generations, creating a strain on society, who would then be entrusted with the care of the offspring.¹⁰⁴ In the end, an 8-1 majority upheld the statute. Justice Oliver Wendell Holmes announced the opinion of the Court, and justified the

92. See *Griswold v. Connecticut*, 381 U.S. 479, 482–86 (1965).

93. See *Skinner*, 316 U.S. at 538.

94. See *id.* at 545 (Stone, C.J., concurring).

95. For an expansive recitation of the case law, see Sarah L. Dunn, Note, *The "Art" of Procreation: Why Assisted Reproduction Technology Allows for the Preservation of Female Prisoners' Right to Procreate*, 70 FORDHAM L. REV. 2561, 2565–71 (2002).

96. *Eisenstadt v. Baird*, 405 U.S. 438, 453 (1972).

97. See *Parham v. J.R.*, 442 U.S. 584, 631 (1979) (asserting that a child's constitutional right to an abortion dwarfs notions of parental authority and autonomy); see also Elizabeth S. Scott, *Sterilization of Mentally Retarded Persons: Reproductive Rights and Family Privacy*, 1986 DUKE L.J. 806, 834 n.96 (listing Supreme Court examples). But see *Planned Parenthood of Cent. Mo. v. Danforth*, 428 U.S. 52, 75 (1976) (cautioning that the child's right to effectively consent to an abortion is not absolute).

98. See, e.g., *Skinner*, 316 U.S. at 538, 541 (overturning the statute for equal protection reasons).

99. See MARTHA A. FIELD & VALERIE A. SANCHEZ, EQUAL TREATMENT FOR PEOPLE WITH MENTAL RETARDATION: HAVING AND RAISING CHILDREN 80 (1999).

100. See NAT'L INST. ON MENTAL RETARDATION, STERILIZATION AND MENTAL HANDICAP: PROCEEDINGS OF A SYMPOSIUM SPONSORED BY THE NATIONAL INSTITUTE ON MENTAL RETARDATION AND THE ONTARIO ASSOCIATION FOR THE MENTALLY RETARDED 89 (1980) [hereinafter *STERILIZATION AND MENTAL HANDICAP*].

101. 274 U.S. 200 (1927).

102. *Id.* at 205.

103. *Id.* But see Paul A. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v. Bell*, 60 N.Y.U. L. REV. 30, 61 (1985) (indicating that Carrie's daughter was not mentally incompetent).

104. *Buck*, 274 U.S. at 205–06.

result by infamously proclaiming, "Three generations of imbeciles are enough."¹⁰⁵

Despite its seeming acceptance of government-sponsored eugenics, *Buck* remains good law today. Fifteen years later, the Supreme Court in *Skinner v. Oklahoma ex rel. Williamson* overturned a statute permitting the involuntary sterilization of "habitual criminals," but the Court declined to overturn *Buck*, and opted to distinguish it instead.¹⁰⁶ In *Roe v. Wade*, the Court used *Buck* as support for the proposition that the right to privacy is not unlimited.¹⁰⁷ Nonetheless, the Court has recognized that *Buck* promotes harsh and extreme measures, and that no state has continued to require such a level after 1990.¹⁰⁸ The legal standards governing the sterilization of incompetent individuals remains haunted by *Buck*'s sanction of eugenics, and this legacy inevitably affects judges considering petitions involving sterilization.¹⁰⁹

4. The Parental Right to Raise Children

The Constitution protects parents' right to raise children.¹¹⁰ In *Pierce v. Society of Sisters*, the Supreme Court recognized that parents have the right to nurture and guide their children's upbringing in the context of education.¹¹¹ Twenty years later in *Prince v. Massachusetts*, the Court explicitly recognized that "the custody, care and nurture of the child reside first in the parents."¹¹²

The right of parents to decide for their children is not inviolate.¹¹³ "In our society, parental rights are limited by the legitimate rights and interests of their children."¹¹⁴ Parents do not have free reign to neglect or abuse their child, alienate his or her property, withhold essential medical treatment, or deny their child the opportunity to encounter new ideas and experiences.¹¹⁵ Any medical decision involving sterilization will conflict

105. *Id.* at 207.

106. *Skinner v. Oklahoma ex rel. Williamson*, 316 U.S. 535, 542 (1942).

107. *Roe v. Wade*, 410 U.S. 113, 154 (1973).

108. *Univ. of Ala. v. Garrett*, 531 U.S. 356, 369 n.6 (2001).

109. See FIELD & SANCHEZ, *supra* note 99, at 78 ("[C]ourt decisions allowing sterilization sometimes rely on eugenic concerns (such as the need to prevent the birth of 'defective' offspring) as a supporting reason. Many courts believe it would be unconstitutional to sterilize as a punishment for crime, but nonetheless hold the state has a valid interest in sterilizing those thought to have retardation." (citing *In re Sterilization of Moore*, 221 S.E.2d 307 (N.C. 1976))).

110. *E.g.*, *Quilloin v. Walcott*, 434 U.S. 246, 255 (1978) ("We have recognized on numerous occasions that the relationship between parent and child is constitutionally protected."); see also *Meyer v. Nebraska*, 262 U.S. 390, 399, (1923) (interpreting the Due Process Clause broadly to protect an individual's right to raise children).

111. *Pierce v. Soc'y of Sisters*, 268 U.S. 510, 534-35 (1925).

112. *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944).

113. *Id.* at 166 & nn.9-11.

114. *Parham v. J.R.*, 442 U.S. 584, 630 (1979).

115. *Id.* at 630-31 & nn.16-19 (citing case law supporting the protection of children's rights).

with the fundamental right to procreate and control one's own reproduction.¹¹⁶ When a child is mentally incompetent, her incapacity may prevent her from making some informed and autonomous decisions, yet allow decision making in other areas.¹¹⁷ When a child is so profoundly incompetent that she is entirely incapable of making decisions and wholly reliant on her parents, courts may step in to restrict the parents' ability to affect their child's reproductive rights.¹¹⁸

B. *Legal Standards Governing Cases Involving the Sterilization of Profoundly Incompetent Children*

Courts have used two primary legal standards when assessing a petition to sterilize an incompetent child: the "substituted judgment" standard and the "best interests" test.¹¹⁹ These standards are used to police different kinds of surrogate decision making. To accommodate the many factual situations that may present themselves, these standards must be flexible. As Part II illuminates, courts may give greater weight to different considerations depending on the facts of an individual case.¹²⁰ But first, parts I.B.1 and I.B.2 describe the standards in their unaltered and purest states.

1. The Substituted Judgment Analysis: Whose Judgment Are We Substituting?

Courts applying the substituted judgment standard do not substitute the judgment of a competent person for that of an incompetent person.¹²¹ To do so would deny the incompetent person of the fundamental right to

116. See *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942) (calling the right to procreate a basic liberty that would be forever deprived from an individual who undergoes unwanted sterilization).

117. See CANTOR, *supra* note 72, at 2 (describing how mentally disabled individuals may be excluded from decisions involving high cognitive ability, but are still capable of exercising a definite preference in other areas).

118. See Scott, *supra* note 97, at 857 (describing how courts traditionally have rejected the parents' suggestions for medical treatment if those suggestions conflict with an important interest of the child).

119. See PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMEDICINAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS 132 (1983) [hereinafter THE COMMISSION REPORT], available at http://www.bioethics.gov/reports/past_commissions/deciding_to_forego_tx.pdf; CANTOR, *supra* note 72, at 41-42. This Note focuses on judicially created legal standards, but a similar inquiry outside the focus of this Note is how the "Ashley Treatment" fits within the framework of states that have sterilization statutes. Today, eighteen states have enabling statutes that expressly authorize a court to order the sterilization of a person with mental disabilities. For a list of the state statutes, see 49 AM. JUR. 3D *Proof of Facts* § 101 n.52 (1998).

120. See generally *infra* Part II.

121. See *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 613 (N.Y. 1988) ("[N]o person or court should substitute its judgment as to what would be an acceptable quality of life for another." (citing *People v. Eulo*, 472 N.E.2d 286, 296 (N.Y. 1984))).

control one's destiny.¹²² Rather, substituted judgment "is intended to ensure that the surrogate decision maker effectuates as much as possible the decision that the incompetent patient would make if he or she were competent."¹²³

Substituted judgment originated in England in the case *Ex parte Whitbread*.¹²⁴ *Whitbread* involved an incompetent man, Hinde, and his mercenary family.¹²⁵ Because Hinde was a "lunatic," the court periodically convened to hear requests on how best to manage his estate.¹²⁶ Seizing the opportunity, Hinde's niece requested that the court increase her portion of the estate's distribution.¹²⁷ Lord Eldon granted her petition, reasoning that this is what Hinde would have wanted had he been competent:

[L]ooking at what it is likely the Lunatic himself would do, if he were in a capacity to act, . . . it would naturally be more agreeable to the lunatic, and more for his advantage, that they should receive an education and maintenance suitable to his condition, than that they should be sent into the world to disgrace him as beggars.¹²⁸

Thus, Lord Eldon applied the doctrine of substituted judgment in that he effected the outcome that Hinde would have desired had he been competent.¹²⁹

Despite its unfortunate origin, American courts regularly apply the doctrine of substituted judgment to cases involving a petition to make medical decisions on behalf of an incompetent person.¹³⁰ According to the

122. See *Washington v. Glucksberg*, 521 U.S. 702, 744–45 (1997) (citing *Fitzgerald v. Porter Mem'l Hosp.*, 523 F.2d 716, 719–20 (7th Cir. 1975)).

123. *In re Jobes*, 529 A.2d 434, 444 (N.J. 1987).

124. (1816) 35 Eng. Rep. 878 (Ch.).

125. See *id.* at 879 ("For a long series of years the Court has been in the habit, in questions relating to the property of a Lunatic, to call in the assistance of those who are nearest in blood It has, however, become too much the practice that, instead of such persons confining themselves to the duty of assisting the Court with [the Lunatic's] advice and management, there is a constant struggle among them to reduce the amount of the allowance made for the Lunatic, and thereby enlarge the fund which, it is probable, may one day devolve upon themselves.").

126. *Id.*; see also Louise Harmon, *Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgment*, 100 YALE L.J. 1, 18 n.101 (1990) (describing the court's "power of administration" over the management of an incompetent individual's estate).

127. See *Whitbread*, 35 Eng. Rep. at 878; see also Harmon, *supra* note 126, at 19–20 ("While the [*Whitbread*] decision did not mention the amount of her request, it was clear that the niece was asking for more money.").

128. *Whitbread*, 35 Eng. Rep. at 879.

129. *Id.* But see Harmon, *supra* note 126, at 23 (questioning whether the result was proper based on the paucity of evidence that Hinde was close with his family).

130. See *Cruzan v. Mo. Dep't of Health*, 497 U.S. 261, 280 (1990) (applying substituted judgment to a case involving a decision to refuse or stop life-sustaining treatment); *In re Quinlan*, 355 A.2d 647, 663–64 (N.J. 1976) (using the substituted judgment analysis to permit a surrogate to discontinue life support for his incompetent daughter); *Strunk v. Strunk*, 445 S.W.2d 145, 145 (Ky. 1969) (extending the applicability of substituted judgment to compel an incompetent person to donate his organs and tissue to his brother); see also Penney Lewis, *Procedures that Are Against the Medical Interests of Incompetent Adults*, 22 OXFORD J. LEGAL STUD. 575, 584 (2002).

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "when possible, decisionmaking for incapacitated patients should be guided by the principle of substituted judgment, which promotes the underlying values of self-determination and well-being better than the best interests standard does."¹³¹

Unlike *Whitbread*, courts properly apply the substituted judgment analysis only in cases where the person once demonstrated competency to make decisions, but became incompetent later due to an accident, illness, or other cause.¹³² Because surrogates must consider the incompetent individual's prior values and preferences (and not those of a reasonable person), a preliminary condition is that the person actually possessed values and preferences.¹³³ For this reason, courts rarely apply the substituted judgment analysis in cases involving children because a child "has no coherent concept of self, let alone a well-articulated system of ends against which we may assess issues of rationality."¹³⁴ Where children are concerned, "substituted judgment is a poor choice of words to describe this decision on behalf of [a] minor child."¹³⁵ Second, in order to properly apply the substituted judgment analysis, it is critical that the previously competent person expressed a preference about a desired course of treatment if he or she were to become incompetent.¹³⁶ There are two possible methods of expression: evidence of an advance directive and clear and convincing evidence of a preference.¹³⁷

Advance directives are more than an expression of preferences or values; they are an act of will, and an expression of deliberate choice.¹³⁸ Advance directives are instructive: A competent person indicates generally or specifically the type or types of medical treatment options he or she chooses to have or not have should he or she become incompetent.¹³⁹ Advance

131. THE COMMISSION REPORT, *supra* note 119, at 136; see *In re Moe*, 432 N.E.2d 712, 720 (Mass. 1982) (indicating that the doctrine of substituted judgment "promotes best the interests of the individual").

132. *Doe ex rel. Tarlow v. District of Columbia*, 489 F.3d 376, 381 (D.C. Cir. 2007); *In re K.I.*, 735 A.2d 448, 455 (D.C. 1999); see CANTOR, *supra* note 72, at 42, 104 (asserting that it is illogical to attempt to replicate the decisions of those people who have always lacked the capacity to make them because there is nothing to replicate).

133. *In re A.C.*, 573 A.2d 1235, 1250 (D.C. 1990) (en banc); CANTOR, *supra* note 72, at 103; see ALLEN E. BUCHANAN & DAN W. BROCK, DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING 120-21 (1989) (describing how courts can determine the evidentiary value of a particular prior expression of a preference).

134. David A.J. Richards, *The Individual, the Family, and the Constitution: A Jurisprudential Perspective*, 55 N.Y.U. L. REV. 1, 24 (1980); see *K.I.*, 735 A.2d at 455 (citing *A.C.*, 573 A.2d 1235; *In re Boyd*, 403 A.2d 744 (D.C. 1979); *In re Barry*, 445 So. 2d 365 (Fla. 1984)).

135. Frank I. Clark, *Withdrawal of Life-Support in the Newborn: Whose Baby Is It?*, 23 SW. U. L. REV. 1, 36 (1990) (internal quotation marks omitted).

136. See CANTOR, *supra* note 72, at 103 (commenting that, under a substituted judgment analysis, courts may take into account the incompetent person's religious values and philosophical preferences).

137. See BUCHANAN & BROCK, *supra* note 133, at 118-19.

138. *Id.* at 115-16.

139. *Id.* at 95.

directives are either oral or written, but the latter is greatly preferred in order to minimize the potential for fraud, duress, or ambiguity.¹⁴⁰ Examples of written advance directives include living wills or powers of attorney.¹⁴¹ Advance directives of this nature typically are relevant to questions involving the elderly,¹⁴² and therefore, are not particularly helpful when discussing a medical procedure like the “Ashley Treatment.”

It is much more likely that the incompetent person did not clearly express his wishes. When this happens,

a surrogate decisionmaker considers the patient’s personal value system for guidance. The surrogate considers the patient’s prior statements about and reactions to medical issues, and all the facets of the patient’s personality that the surrogate is familiar with—with, of course, particular reference to his or her relevant philosophical, theological, and ethical values—in order to extrapolate what course of medical treatment the patient would choose.¹⁴³

This involves “a synthesis of (1) factors known to be true about the incompetent and (2) other considerations which necessarily suggest themselves when the court cannot be sure about an incompetent’s actual wishes.”¹⁴⁴ Factors that are readily ascertainable may include a person’s religious beliefs,¹⁴⁵ philosophical beliefs,¹⁴⁶ value system, and goals.¹⁴⁷ Other considerations may be “information provided by the patient’s family, and, if applicable, any past decisions the patient may have made regarding medical care.”¹⁴⁸ Thus, courts applying substituted judgment in this way may use these factors to authorize decisions for an incompetent individual that are not necessarily in that individual’s best interests, but nonetheless, represent their preference.¹⁴⁹

When the only evidence courts have is circumstantial (and not an advance directive), substituted judgment requires that there be “clear and

140. *Id.* at 118.

141. *Id.* at 95, 295. Living wills are called instructional advance directives while powers of attorney are called proxy advance directives. *Id.* at 95.

142. *Id.* at 296.

143. *In re Jobes*, 529 A.2d 434, 444 (N.J. 1987) (citing *In re Roe*, 421 N.E.2d 40, 56–59 (Mass. 1981)) (footnote omitted).

144. *In re Boyd*, 403 A.2d 744, 751 (D.C. 1979).

145. *See id.*

146. CANTOR, *supra* note 72, at 103.

147. *Does v. District of Columbia*, 374 F. Supp. 2d 107, 113 (D.D.C. 2005).

148. *Id.*

149. *In re Roe*, 421 N.E.2d 40, 59–60 n.20 (Mass. 1981) (“[I]f an individual would, if competent, make an unwise or foolish decision, the judge must respect that decision as long as he would accept the same decision if made by a competent individual in the same circumstances.”); see D. Don Welch, *Walking in Their Shoes: Paying Respect to Incompetent Patients*, 42 VAND. L. REV. 1617, 1629 (1989) (recognizing that people often do not make decisions in their best interests, and the third-party surrogate’s responsibility is to give respect to the incompetent person’s particular preference).

convincing" evidence of the incompetent person's preference.¹⁵⁰ The Supreme Court in *Cruzan v. Missouri Department of Health* defined clear and convincing evidence as that which

produces in the mind of the trier of fact a firm belief or conviction as to the truth of the allegations sought to be established, evidence so clear, direct and weighty and convincing as to enable [the factfinder] to come to a clear conviction, without hesitancy, of the truth of the precise facts in issue.¹⁵¹

Many commentators argue that it is impossible to enter the mind of another whose experiences are so dramatically different.¹⁵² Rebecca Dresser explains, "The greater the difference between the experiencer and her observer, the less it is possible for the observer to adopt the experiencer's point of view."¹⁵³ For this reason, if clear and convincing evidence of a preference is lacking, substituted judgment may not be used¹⁵⁴ because "many of us harbor severe doubts about the ability of our families, friends, and caregivers to gain access to the information they would need to make decisions that truly protected our welfare as incompetent patients."¹⁵⁵

2. The Best Interests Test: Separating Good Interests from Best Interests?

Unlike the substituted judgment doctrine, the best interests test is an objective inquiry.¹⁵⁶ The best interests analysis requires that courts examine how a particular medical procedure will affect an incompetent person mentally and physically, and determine whether such changes will bring an overall improvement to the person's quality of life.¹⁵⁷ Thus, it is a comparative test:

150. *Cruzan v. Mo. Dep't of Health*, 497 U.S. 261, 284 (1990); *V.S.D. v. Williams-Huston*, 660 N.E.2d 1064, 1067-68 (Ind. Ct. App. 1996); *In re Debra B.*, 495 A.2d 781, 783 (Me. 1985).

151. *Cruzan*, 497 U.S. at 285 n.11 (quoting *In re Jobes*, 529 A.2d 434, 441 (N.J. 1987)) (alteration in original).

152. See Rebecca Dresser, *Missing Persons: Legal Perceptions of Incompetent Patients*, 46 RUTGERS L. REV. 609, 669-70 (1994) (describing the impossibility of comprehending the "inner worlds of other subjects of experience" by way of an example). Cf. THOMAS NAGEL, *What Is It Like to Be a Bat?*, 83 PHIL. REV. 435 (1974), reprinted in MORTAL QUESTIONS 165 (1979).

153. Dresser, *supra* note 152, at 670.

154. See *Wentzel v. Montgomery Gen. Hosp., Inc.*, 447 A.2d 1244, 1249 (Md. 1982) (noting that sterilization rarely is in the best interests of the incompetent person). But see *In re Wirsing*, 573 N.W.2d 51, 55 (Mich. 1998) (declining to require clear and convincing evidence).

155. Dresser, *supra* note 152, at 672.

156. See CANTOR, *supra* note 72, at 107 (articulating that the best interests inquiry is what a reasonable incompetent person would do under similar circumstances).

157. See William A. Kraus, Note, *The Incompetent Developmentally Disabled Person's Right of Self-Determination: Right-to-Die, Sterilization and Institutionalization*, 15 AM. J.L. & MED. 333, 351-52 (1989) (explaining how the best interests analysis forces courts to balance the advantages and disadvantages of a particular course of treatment); see also *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417, 428 (Mass. 1977).

[T]he best interest[s] principle instructs us to determine the *net* benefit for the patient of each option, assigning different weights to the options to reflect the relative importance of the various interests they further or thwart, then subtracting costs or “disbenefits” from the benefits for each option. The course of action to be followed, then, is the one with the greatest net benefit to the patient. The mere fact that a treatment would benefit the patient is not sufficient to show that it would be in the individual’s best interests, since other options may have greater net benefits, or the costs of the option to the patient—in suffering and disability—may exceed the benefit.¹⁵⁸

The analysis can be complicated by the fact that a surrogate must objectively assess the best interests of an incompetent person.¹⁵⁹ Logically, it is extremely difficult for the guardian to distort his perspective in such a drastic way because of the difference between their frames of reference.¹⁶⁰

Courts consider a number of factors under the best interests test:

In assessing whether a procedure or course of treatment would be in a patient’s best interests, the surrogate must take into account such factors as the relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of life sustained. An accurate assessment will encompass consideration of the satisfaction of present desires, the opportunities for future satisfactions, and the possibility of developing or regaining the capacity for self-determination.

The impact of a decision on an incapacitated patient’s loved ones may be taken into account in determining someone’s best interests, for most people do have an important interest in the well-being of their families or close associates.¹⁶¹

Courts generally apply the best interests test narrowly rather than broadly, meaning that judges prefer to maintain the status quo rather than approve a risky medical procedure.¹⁶² This is done first and foremost to avoid abuse.¹⁶³ Nonetheless, their prudence inevitably limits surrogates’ ability to authorize certain medical interventions.¹⁶⁴ For example, courts applying the best interests test have rejected surrogates’ petitions to apply

158. BUCHANAN & BROCK, *supra* note 133, at 123.

159. *E.g.*, *In re Quinlan*, 355 A.2d 647 (N.J. 1976); *see* CANTOR, *supra* note 72, at 107 (emphasizing that the surrogate must not cloud their judgment with their own experience as a competent individual).

160. *See* Cantor, *supra* note 3, at 162; Dresser, *supra* note 152, at 667 & n.205.

161. THE COMMISSION REPORT, *supra* note 119, at 135 (citing *In re Roe*, 421 N.E.2d 40, 58 (Mass. 1981) (footnote omitted)).

162. *See* Donna S. Harkness, “Whenever Justice Requires”: Examining the Elusive Role of Guardian Ad Litem for Adults with Diminished Capacity, 8 MARQ. ELDER’S ADVISOR 1, 25–26 (2006).

163. *See* THE COMMISSION REPORT, *supra* note 119, at 136.

164. *See* Lewis, *supra* note 130, at 587–88 (“Procedures other than treatment, which are undertaken for a purpose unrelated to the incompetent person’s welfare, are generally considered to fail the best interests test and are therefore not permitted.”).

lifesaving medical treatment,¹⁶⁵ to remove lifesaving medical treatment,¹⁶⁶ to remove an organ and transplant it into another family member,¹⁶⁷ to perform nontherapeutic research,¹⁶⁸ and to sterilize.¹⁶⁹ One commentator suggests that this tentativeness stems from the idea that courts are unsure whose interests deserve greater merit—those of the incompetent individual herself or the general rights of human beings as measured by society.¹⁷⁰ This collision is inevitable, she argues, especially when the incompetent individual's interests are in direct conflict with those of society.¹⁷¹ Professor Dresser explains,

If we can count as relevant interests only what patients themselves experience, then the best interests standard will require aggressive care for "persons" that are little more than objects in the world." On the other hand, if choices are made solely according to what matters to human beings in general, if relatively sophisticated concerns such as dignity and privacy are deemed to justify nontreatment, then it seems that the vast majority of mentally impaired patients' lives will be placed in jeopardy.¹⁷²

In other words, courts, as instruments of society, cannot completely discount those normative values when applying the best interests test. They swoop in undetected and inevitably impact judicial decision making.¹⁷³

For cases involving the sterilization of an incompetent minor, courts have typically followed a general pattern, such as that followed in the case of *In re Grady*.¹⁷⁴ First, the ultimate duty to decide whether sterilization is in the best interests of the child remains with the court, and not the child's

165. *In re K.I.*, 735 A.2d 448, 450 (D.C. Cir. 1999) (affirming the trial court's ruling that the issuance of a "do not resuscitate" order was in the best interests of the infant child despite her mother's objection).

166. See *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977). For a discussion of the facts of *Saikewicz*, see *infra* text accompanying notes 200–16.

167. See *In re Richardson*, 284 So. 2d 185, 187 (La. Ct. App. 1973) (rejecting the court's analysis in *Strunk v. Strunk*); see also *In re Pescinski*, 226 N.W.2d 180 (Wis. 1975). But see *Hart v. Brown*, 289 A.2d 386 (Conn. Super. Ct. 1972) (authorizing organ transplant surgery); *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. 1969) (same); *In re Doe*, 481 N.Y.S.2d 932 (App. Div. 1984) (same); *Little v. Little*, 576 S.W.2d 493 (Tex. Cir. App. 1979) (same).

168. See generally *Lewis*, *supra* note 130.

169. See *In re Romero*, 790 P.2d 819, 823 (Colo. 1990); *In re Grady*, 426 A.2d 467, 486 (N.J. 1981); *In re Terwilliger*, 450 A.2d 1376, 1383–86 (Pa. Super. Ct. 1982); *In re Hayes*, 608 P.2d 635, 641–42 (Wash. 1980).

170. See *Dresser*, *supra* note 152, at 657–58.

171. See *id.* at 658–59 (describing the dual natures of the best interests inquiry); see also *id.* at 658 ("The problem is inescapable because it is impossible to separate the incompetent patient's current interests from a more general conception of the interests of human beings.").

172. *Id.* at 659 (quoting Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 409 (1988)).

173. *Id.* at 661 ("It is disingenuous to contend that the best interests approach can be completely separated from broader social judgments about what gives life value to human beings.").

174. 426 A.2d 467; see also *Terwilliger*, 450 A.2d at 1385; *Hayes*, 608 P.2d at 641.

parents.¹⁷⁵ Second, the court must appoint an independent *guardian ad litem*, and also meet with the incompetent child.¹⁷⁶ Third, the party requesting sterilization must prove by clear and convincing evidence that the individual is incapable of making a decision about sterilization and that this inability is unlikely to improve in the foreseeable future.¹⁷⁷ If these initial hurdles are overcome, a court will ultimately determine whether sterilization is in the best interests of the incompetent child.¹⁷⁸

Incapacity must be proven, and is never assumed: because an individual lacks the capacity to make one kind of decision does not automatically mean that she lacks capacity for another decision.¹⁷⁹ What does it mean to lack capacity to consent to sterilization? A technical understanding of the surgical procedure and its risks is not necessary.¹⁸⁰ A person need not understand the attendant risks and complications of pregnancy and childbirth.¹⁸¹ Even a low intelligence quotient does not permit the inference that the person lacks the capacity to consent to sterilization.¹⁸² What is required is that the incompetent person understands that sterilization involves a surgical procedure, and that the procedure will result in an inability to bear children.¹⁸³

If a court is satisfied that the foregoing factors are met, the court will make the ultimate determination of whether sterilization is in the best interests of the incompetent child.¹⁸⁴ Courts typically assess the following nine factors offered in *Grady* for cases involving requests to sterilize an incompetent child:

175. See *Grady*, 426 A.2d at 482 (citing U.S. Supreme Court cases that recognize a parent's involvement and interest in their child's decisions, but asserting that this interest must yield to the child's right to control his or her own reproduction).

176. *Id.* (charging the guardian with a duty of meeting with the child and offering evidence and witnesses at the hearing, and advocating that judges meet with the child to construct their own impressions of competency); see BLACK'S LAW DICTIONARY 725 (8th ed. 2004) (defining *guardian ad litem* as one who appears in court on behalf of an incompetent or minor party).

177. See *Grady*, 426 A.2d at 482–83 (noting that varying degrees of mental disability can make people legally incompetent to make some decisions, but capable of comprehending the decision to sterilize); see also *In re Romero*, 790 P.2d 819, 822 (Colo. 1990); *In re Moe*, 432 N.E.2d 712, 721 & n.7 (Mass. 1982) (indicating that delaying sterilization may have adverse consequences in some situations).

178. See *Grady*, 426 A.2d at 483 (presenting nine factors that the court should consider, but recognizing that these factors are not exclusive); *infra* text accompanying note 185 (listing the specific factors considered in *Grady*).

179. *Id.*; see BUCHANAN & BROCK, *supra* note 133, at 18–19.

180. *Romero*, 790 P.2d at 823; *Moe*, 432 N.E.2d at 721–22 n.8.

181. *Romero*, 790 P.2d at 823.

182. Cf. *In re Terwilliger*, 450 A.2d 1376, 1385 (Pa. Super. Ct. 1982). Mildred Terwilliger had an I.Q. of thirty-three, but expressed an understanding of the consequences of sterilization. The case was remanded for greater fact finding. *Id.* at 1386.

183. Larry O. Gostin, *Consent to Involuntary and Non-medically Indicated Sterilization of Mentally Retarded Adults and Children*, in STERILIZATION AND MENTAL HANDICAP, *supra* note 100, at 38, 40.

184. See *Grady*, 426 A.2d at 483. Courts may also order sterilization based on a finding of clear and convincing evidence that the procedure is “medically essential.” *In re A.W.*, 637 P.2d 366, 375 (Colo. 1981) (en banc).

- Whether pregnancy is possible;
- Whether pregnancy or sterilization will cause the child trauma or psychological damage;
- The likelihood that the child will encounter forced or consensual sexual situations;
- The child's capacity to comprehend reproduction or contraception, and the likelihood it will change;
- Whether medical advances in the present or foreseeable future will offer any less drastic methods;
- Whether postponement of sterilization at the time of the petition is advisable;
- Whether the child will be able to care for a baby on her own or with a marital partner;
- Whether any medical breakthroughs are expected that could improve the person's condition or make sterilization less drastic; and
- A showing that the petitioners seek sterilization of the ward in good faith and in her best interests, rather than for their own or society's benefit.¹⁸⁵

Courts will weigh these nonexhaustive factors "as the particular circumstances dictate."¹⁸⁶ When considered in totality, they must demonstrate by clear and convincing evidence that sterilization is in the child's best interests.¹⁸⁷

II. THE DIVERSE APPLICATION OF THE SUBSTITUTED JUDGMENT AND BEST INTERESTS TEST

Part I described the current constitutional constraints on courts deciding sterilization cases involving profoundly incompetent children and the legal standards that have developed as a result of that jurisprudence. While the substituted judgment standard asks, "What would this patient choose if she were competent?"¹⁸⁸ the best interests test attempts to determine "what a reasonable person with the characteristics of the incompetent would [do] under similar circumstances."¹⁸⁹ However, assuming the perspective of an incompetent individual, whether objective or subjective, poses several

185. *Grady*, 426 A.2d at 483.

186. *Id.*

187. *Id.* at 486.

188. See Dresser, *supra* note 152, at 616 (internal quotation marks omitted).

189. CANTOR, *supra* note 72, at 107 (quoting Paul B. Solnick, *Proxy Consent for Incompetent Non-Terminally Ill Adult Patients*, 6 J. LEGAL MED. 1, 15 (1985)).

problems.¹⁹⁰ Part II describes how courts have varied their application of these legal standards depending upon the particular facts of the case. Part II.A.1 describes how courts may sometimes incorrectly apply the best interests standard while purporting to apply the substituted judgment standard, thus creating an erroneous hybrid standard. This section also provides one specific case example of this hybrid approach. Part II.A.2 asserts that the rationale behind this hybrid approach may be understandable, but as a result, it has created confusing judicial precedent in an area of rising importance. Part II.B indicates how one commentator has attempted to resolve the confusion by applying a best interests test that emphasizes extrinsic concerns that are particularly relevant to the incompetent individual at issue. Part II.B provides another case example which demonstrates how an emphasis on extrinsic considerations may permit courts to authorize extreme medical procedures in limited situations. However, other legal commentators have argued that courts cannot simply rely on extrinsic factors, but must balance them against other more objective standards when making their decisions. Part II.C explains their theories and the reasons behind them.

A. The Hybridization of the Substituted Judgment and Best Interests Analyses

1. Confusing the Doctrines

Courts often combine the substituted judgment analysis with the best interests test, creating a hybrid¹⁹¹ substituted judgment-best interests test.¹⁹² When hybridization occurs, the court asserts its intention to apply the substituted judgment analysis, but actually applies a best interests analysis.¹⁹³ This happens when a court improperly uses the best interests test to determine the interests of a never-competent individual or an individual who lost competency, but never expressed a preference.¹⁹⁴ In these instances, because courts have no indication of a preference, courts perform a weighing analysis that compares the person's present situation

190. *Id.* at 107–13.

191. See, e.g., Adam Marshall, Comment, *Choices for a Child: An Ethical and Legal Analysis of a Failed Surrogate Birth Contract*, 30 U. RICH. L. REV. 275, 296 (1996). Norman L. Cantor refers to this type of analysis as a “melding or blending of the substituted-judgment and best-interests standards.” See CANTOR, *supra* note 72, at 42.

192. See, e.g., *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417, 431 (Mass. 1977); see also *Strunk v. Strunk*, 445 S.W.2d 145, 148 (Ky. 1969); *Wentzel v. Montgomery Gen. Hosp., Inc.*, 447 A.2d 1244, 1259 (Md. 1982).

193. See Alan B. Handler, *Individual Worth*, 17 HOFSTRA L. REV. 493, 514 (1989) (characterizing the hybrid analysis as “a best interest[s] analysis . . . cloaked in a substituted-judgment formulation”); see also Stewart G. Pollock, *Life and Death Decisions: Who Makes Them and by What Standards?*, 41 RUTGERS L. REV. 505, 525–30 (1989).

194. See BUCHANAN & BROCK, *supra* note 133, at 113–15 (describing the two instances of misapplication).

with the potential future gains.¹⁹⁵ In weighing the pros and cons of a particular medical procedure, the court is attempting to fill in the missing pieces that are left either because the person was born incompetent, or because he neither expressed a prior preference nor developed a value system.¹⁹⁶ Courts indicate that they are applying the substituted judgment analysis by "don[ning] the mental mantle of the incompetent," leading to a result that is in conformity with the incompetent individual's values and belief system.¹⁹⁷ In actuality, however, courts are not assuming the individual's point of view. Instead, the court is performing a best interests-type analysis that weighs the person's future pleasure and pain in an attempt to project what the person would have desired.¹⁹⁸ The result, one commentator asserts, is an obvious fabrication.¹⁹⁹

A clear example of this hybrid application is *Superintendent of Belchertown v. Saikewicz*.²⁰⁰ Joseph Saikewicz was sixty-seven years old, profoundly incompetent since birth,²⁰¹ and suffering from a fatal type of leukemia.²⁰² Saikewicz's *guardian ad litem*²⁰³ requested permission to withhold chemotherapy treatment from Saikewicz despite the fact that it was the advised course of treatment.²⁰⁴ The *guardian ad litem* explained his decision was based on evidence that Saikewicz could not comprehend the medicinal benefits of the treatment, but would experience all the pain and fear associated with chemotherapy.²⁰⁵

In addition to the guardian's testimony, several factors strongly suggested that chemotherapy treatment was not in Saikewicz's best interests.²⁰⁶ First, his age made it more likely that he would not tolerate chemotherapy as well as a younger person.²⁰⁷ Second, there were probable side effects to chemotherapy, such as severe nausea, bladder irritation,

195. CANTOR, *supra* note 72, at 160; *see also id.* at 106.

196. *See In re Boyd*, 403 A.2d 744, 751 (D.C. 1979) (citing *Saikewicz*, 370 N.E.2d at 430); *see also* CANTOR, *supra* note 72, at 103.

197. *In re Carson*, 241 N.Y.S.2d 288, 289 (Sup. Ct. 1962); *see also Saikewicz*, 370 N.E.2d at 430-31.

198. *See* CANTOR, *supra* note 72, at 105 (relying on the best interests test of the incompetent individual in the absence of an articulated choice).

199. *See* Joel Feinberg, *Wrongful Life and the Counterfactual Element in Harming*, 4 SOC. PHIL. & POL'Y 145 (1986), *reprinted in* FREEDOM AND FULFILLMENT 3, 20-23 (1992). *But see* Lewis, *supra* note 130, at 616 ("It is not that we are lying in these cases; we are genuinely torn. . . . [W]hen we are forced to compromise, we need to hide the trade-off and to profess continued respect for the value that lost out.") (quoting Richard W. Garnett, *Why Informed Consent? Human Experimentation and the Ethics of Autonomy*, 36 CATH. LAW. 455, 487 (1996)).

200. 370 N.E.2d 417.

201. *Id.* at 420, 430 (indicating that Saikewicz had an I.Q. of ten, a mental age of approximately two years and eight months, and had been "noncommunicative" since birth).

202. *See id.* at 420-21.

203. *See supra* note 176.

204. *Saikewicz*, 370 N.E.2d at 419.

205. *Id.* at 430.

206. *See id.* at 432 (describing how the court considered Saikewicz's age, improbability of recovery, side effects, and present and future comfort).

207. *Id.* at 432 n.17.

numbness and tingling of his extremities, and hair loss.²⁰⁸ Third, there was a low likelihood that chemotherapy would cause the cancer to go into remission.²⁰⁹ Fourth, the record clearly indicated that chemotherapy treatment would definitely cause immediate suffering.²¹⁰ Fifth, Saikewicz had resisted treatment in the past, and the record revealed this resistance was based on the fear, confusion, and pain the treatment caused.²¹¹ Lastly, the judge concluded that Saikewicz's subjective quality of life would decrease if he were given the treatment because the treatment would disorient and frighten him.²¹² The judge considered these factors against the reasons provided for administering chemotherapy treatment—that most people choose to endure chemotherapy and the potential to live a longer life.²¹³ The court weighed the reasons for and against the treatment plan, and ultimately concluded that Saikewicz would have performed this same balancing test had he been competent.²¹⁴ The court rationalized the result by associating Saikewicz with the same mental processes of a competent person.²¹⁵ In theory, this effort was to “afford to that person the same panoply of rights and choices [that the state] recognizes in competent persons.”²¹⁶

Saikewicz exemplifies this hybrid type of application because the court concluded that the correct application of substituted judgment was to determine the decision that “would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual”²¹⁷ The court asserted its intention to apply the substituted judgment analysis despite having no evidence of Saikewicz's preference for or against chemotherapy.²¹⁸ Substituted judgment requires that the court determine precisely what Saikewicz would have elected if he were competent. Instead, however, the court weighed reasons for and against treating Saikewicz with chemotherapy.²¹⁹ This kind of analysis embodies more of a best interests test.²²⁰ The *Saikewicz* court assumed that had Saikewicz been competent, he would have performed this weighing analysis and decided that chemotherapy was not in his best

208. *Id.* at 421.

209. *Id.*

210. *Id.* at 432.

211. *Id.*

212. *Id.*

213. *Id.* at 431.

214. *Id.*

215. *See, e.g., id.* at 431–42 (asserting that four of the six factors weighing against chemotherapy treatment were “considerations that any individual would weigh carefully”); *see also supra* text accompanying notes 124–29.

216. *Saikewicz*, 370 N.E.2d at 428.

217. *Id.* at 431.

218. *Id.* at 428.

219. *Id.* at 431–32.

220. *See supra* text accompanying note 158.

interests.²²¹ Therefore, the *Saikewicz* court applied a best interests weighing test rather than requiring an advance directive or clear and convincing evidence of a preference. The court "selected a medical course for [Saikewicz] that the court believed would best promote [his] interests in avoiding suffering . . . and deriving satisfaction or pleasure from existence."²²²

2. The Rationale Behind the Hybrid Analysis

As Part II.A.1 alluded, the hybrid analysis is a best interests test disguised as substituted judgment. Why do courts mistakenly indicate that they are performing a substituted judgment analysis when they really are performing a best interests analysis? One reason to perform a hybrid application is to satisfy a societal interest in protecting a profoundly incompetent individual's personal autonomy rights.²²³ The substituted judgment analysis is preferred over the best interests test because it "promotes the underlying values of self-determination and well-being better than the best interests standard does."²²⁴ Applying substituted judgment implements the individual's prior choice whereas the best interests test merely attempts to discern it. By purporting to apply the substituted judgment test, the court may be trying to validate its argument by describing the treatment as the patient's choice, even though there is no evidence of that conclusion.²²⁵ Giving effect to a proposal that is the patient's choice is a relief to judges when the proposal is consistent with the patient's existing condition.²²⁶

Another reason is that inborn profoundly incompetent individuals have never developed preferences, beliefs, or a system of values.²²⁷ Therefore, surrogate decision making for these individuals is limited to the best interests test. The best interests test is objective, requiring that the "surrogate decisionmaker . . . choose a course that will promote the patient's well-being as it would probably be conceived by a reasonable

221. See *Saikewicz*, 370 N.E.2d at 431-32 (stating that *Saikewicz* would, like any individual, weigh the pros and cons of the treatment and ultimately conclude that he was better off without chemotherapy).

222. See Cantor, *supra* note 3, at 160.

223. See BUCHANAN & BROCK, *supra* note 133, at 113 (describing how two cases rationalized applying substituted judgment to an incompetent person who had never expressed a preference because to not do so would deny that person of a fundamental right); see, e.g., *supra* text accompanying note 216.

224. THE COMMISSION REPORT, *supra* note 119, at 136.

225. See generally *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. 1969) (authorizing the removal of a kidney from an incompetent person so that it could be transplanted into his brother).

226. Dresser, *supra* note 152, at 624. ("When a directive is consistent with the best interests and reasonableness standards . . . decisionmakers, relieved at the opportunity to escape the full psychological burden of responsibility for determining the patient's fate, are typically happy to honor it. . . . [T]hese directives are welcome reinforcements of what seem to most of us good decisions, given the circumstances.").

227. See *supra* note 3.

person in the patient's circumstances."²²⁸ Surrogates "must scrupulously adhere to the disabled person's perspective in discerning the levels of suffering and gratification actually present (or foreseeable) in any individual case."²²⁹ Performing this assessment is much easier said than done.

Professor Dresser describes how courts have attempted this feat. First, courts hear evidence on the person's medical condition or disability and how caregivers, family, and medical staff have interacted with the person.²³⁰ Using this information, the judge "filters" the information using his own "moral lens" to decide what the evidence reveals about the incompetent individual's own subjective experience.²³¹ Many times, the filtration process reveals contradictory results.²³² This is especially true when courts analyze cases involving semiconscious and conscious individuals who cannot clearly provide guidance.²³³

Dresser is dissatisfied with this method because the judge's sense of morality has a direct impact on how he or she will resolve the case:

Because the patients themselves are incapable of describing what their lives are like, there is fertile ground for disagreement. What is "known" about a patient is malleable, molded by the observers' own views on whether treatment could provide the patient with a life worth living. Quality of life constitutes the ineluctable lens through which judges perceive incompetent patients.²³⁴

Differing notions of morality and extreme surrogate requests create inconsistency in the case law and reinforce the uncertainty of profoundly incompetent individuals' realities.²³⁵ But because morality is linked to a number of constitutional guarantees, completely disregarding it would be improper.²³⁶ How then do judges use their notions of morality to bring consistency to the case law?

B. A Whole New World: Shifting the Focus to Emphasize Extrinsic Concerns that Are Relevant to the Particular Individual

Many applications of the best interests test have emphasized extrinsic considerations. Penney Lewis explains that extrinsic considerations are those interests that "focus[] on the incompetent person's psychological and social interests."²³⁷ Examples of psychological interests include the interest

228. THE COMMISSION REPORT, *supra* note 119, at 136.

229. Cantor, *supra* note 3, at 161.

230. Dresser, *supra* note 152, at 640.

231. *Id.* at 640-43.

232. *Id.* at 641-42 (describing three examples).

233. *See id.* at 643-47.

234. *Id.* at 647.

235. *Id.* at 642-47.

236. *See* Joel Feinberg, *In Defense of Moral Rights: Their Constitutional Relevance*, in FREEDOM AND FULFILLMENT *supra* note 199, at 245.

237. Lewis, *supra* note 130, at 588.

in maintaining a close emotional relationship with another, the interest in receiving continued care from another, and the interest in receiving improved medical care.²³⁸ When examining psychological interests like these, Professor Lewis cautions that "care must be taken to avoid this benefit being presumed rather than proved. . . . [because] such benefits are difficult to predict, speculative and lacking in evidentiary support."²³⁹

Social interests are those that should be "encouraged and facilitated" because such a procedure is a "societal good."²⁴⁰ For these interests to come into play, the treatment proposed must be in the best interests of the incompetent individual.²⁴¹ If the incompetent person expressed a prior preference, permitting the use of the substituted judgment standard, then the proposed procedure may be authorized even if it is not in the person's best interests.²⁴² If the procedure is a societal interest, but it is not in the best interests of the incompetent person, and the situation is not one where the substituted judgment standard may be used, the procedure may still be lawful. In this instance, "[a]dditional criteria might also be imposed, such as that the harm to the incompetent person not be greater than a specified threshold, or that the incompetent person does not dissent."²⁴³ The Law Commission of England and Wales has considered using societal interest as a means of promoting a procedure not in the best interests of an incompetent individual, such as elective ventilation and genetic screening.²⁴⁴

Professor Dresser offers a standard that she calls a "revised best-interests principle," which "both protects patients' experiential welfare and permits surrogate decisionmakers to choose from an array of reasonable treatment options."²⁴⁵ The revised best-interests principle attempts to "stand in the patient's shoes, to understand the situation as it is for her," and also "permit us to exercise empathy in the context of a broader community to which the patient belongs."²⁴⁶ This "broader community" to which Dresser refers is actually the small subjective world in which the incompetent person lives.²⁴⁷ She explains that some individuals are so extremely impaired that their disability breaks that person's connection to the outside world, permitting treatment options that ordinarily may be considered extreme for competent individuals, but are reasonable for profoundly incompetent ones:

Some impaired patients can be kept alive only if they are substantially restrained, sedated, or otherwise restricted. If the necessary restrictions are extreme, and no less drastic means of treatment delivery are available,

238. *See generally id.* at 588-93.

239. *Id.* at 589 (citations and internal quotation marks omitted).

240. *Id.* at 596.

241. *Id.*

242. *Id.*

243. *Id.* (citation omitted).

244. *Id.*

245. *See generally* Dresser, *supra* note 152, at 617.

246. *Id.* at 665.

247. *Id.*

the best interests standard should permit the treatment to stop. Similarly, the best interests standard should leave room for nontreatment when a patient's conscious awareness is significantly impoverished, because a near absence of human experiences sufficiently diminishes the value a patient can obtain from life. Such patients are so removed from the human condition that we can defensibly say that a failure to treat is of no harm to them.²⁴⁸

Dresser acknowledges that it is difficult to uncover the subjective experiences of others, but instead of conceding defeat, she advocates "using available tools to investigate and make judgments on how particular patients experience their lives."²⁴⁹ Our everyday life experiences may not be sufficient in cases involving people who are different from ourselves.²⁵⁰ People must combine their "subjective imaginations with the objective knowledge achievable through scientific, clinical, and everyday observation."²⁵¹ Assessments involving conscious incompetent individuals are difficult and demand "extreme caution."²⁵² Nonetheless, Dresser contends that "uncertainty about a patient's mental experiences should not lead to their exclusion from the treatment calculation."²⁵³ After using available tools, it may become clear from the facts that a request that objectively appears extreme is actually subjectively reasonable for the profoundly incompetent patient.

*Strunk v. Strunk*²⁵⁴ demonstrates Dresser's theory that courts may authorize an extreme procedure using an assessment of the incompetent individual's connection to the world based on his incapacity. In *Strunk*, a divided 4-3 court granted two parents' request to transplant one kidney from their incompetent son (Jerry) to their competent son (Tommy).²⁵⁵ Tommy suffered from a fatal kidney disease, and, without the transplant operation, he would die.²⁵⁶ Doctors tested the entire family for a donor match, but only Jerry was a "highly acceptable" donor match.²⁵⁷ Jerry's incompetence caused him to have a speech defect, which limited his ability to communicate with people "not well acquainted with him."²⁵⁸ The court

248. *Id.* at 665-66; *see also* Lewis, *supra* note 130, at 577-78 (describing procedures that may not confer a medical benefit, but provide other benefits).

249. Dresser, *supra* note 152, at 666-81 (articulating several theories offered by philosophers).

250. *Id.* at 668-69. However, Professor John R. Searle contends that we can relate our everyday experiences to differently situated individuals using a "same causes-same effects and similar causes-similar effects" principle. *See id.* at 674-75 (emphasis omitted).

251. *Id.* at 674 (citing NAGEL, *supra* note 152, at 169).

252. *See* Dresser, *supra* note 152, at 698 ("At present, it is impossible to make third-person determinations about the nature of a conscious incompetent patient's experiential world with the same assurance that is possible for determinations that patients are incapable of any experiences at all.").

253. *Id.*

254. 445 S.W.2d 145 (Ky. 1969).

255. *Id.*

256. *Id.* at 145.

257. *Id.* at 146.

258. *Id.*

found that Jerry's I.Q. was approximately thirty-five, giving him the mental age around that of a six-year-old.²⁵⁹ Therefore, consent was an issue, and the parents requested that the court grant permission to proceed with the surgery.²⁶⁰

The majority applied the hybrid analysis, but gave great weight to evidence indicating that the transplant would psychologically benefit Jerry.²⁶¹ Ultimately, the court was convinced by evidence indicating that Tommy represented Jerry's connection to the family, and keeping Tommy alive preserved that connection.²⁶² The Kentucky Department of Mental Health, which entered the case as *amicus curiae*, described the importance of maintaining Jerry's sense of self, which was dependent upon family continuity:

It is difficult for the mental defective to establish a firm sense of identity with another person and the acquisition of this necessary identity is dependent upon a person whom one can conveniently accept as a model and who at the same time is sufficiently flexible to allow the defective to detach himself with reassurances of continuity. His need to be social is not so much the necessity of a formal and mechanical contact with other human beings as it is the necessity of a close intimacy with other men, the desirability of a real community of feeling, an urgent need for a unity of understanding. Purely mechanical and formal contact with other men does not offer any treatment for the behavior of a mental defective; only those who are able to communicate intimately are of value to hospital treatment in these cases. And this generally is a member of the family.²⁶³

The majority in *Strunk* ultimately authorized the kidney transplant because it preserved the family by keeping Tommy alive.²⁶⁴ The "preservation of the family" was the true benefit the operation bestowed upon Jerry because, psychologically, Jerry was able to continue to feel close to another human being.²⁶⁵ The majority considered the disadvantage of the transplant surgery—the risk inherent in removing Jerry's kidney—but concluded that the risk was minimal, equating it to the risk of driving a car

259. *Id.*

260. *Id.*

261. *See id.* at 146, 148–49 (purportedly using substituted judgment, but basing the analysis on a balancing of the risks and benefits of the treatment); *see also* Lynn E. Lebit, Note, *Compelled Medical Procedures Involving Minors and Incompetents and Misapplication of the Substituted Judgment Doctrine*, 7 J.L. & Health 107, 112–14 (1992). This "psychological benefit" has also been recognized outside of the United States. *See* Lewis, *supra* note 130, at 588.

262. *See Strunk*, 445 S.W.2d at 146–47.

263. *Id.* at 146.

264. *See id.* at 147 (indicating that if Tommy died, when his parents died, "Jerry [would] have no concerned, intimate communication so necessary to his stability and optimal functioning") (internal quotation marks omitted).

265. *Id.* at 146–49 (drawing support from English law). *But see In re John Doe*, 481 N.Y.S.2d 932 (App. Div. 1984) (*per curiam*) (permitting a bone marrow transplant from a profoundly incompetent man to his competent brother despite a lack of evidence that the ward was emotionally attached to his brother).

sixteen miles on every working day.²⁶⁶ The dissent attacked the majority's emphasis on "nebulous" psychological benefits, and concluded that the likelihood that the transplant surgery would be a success was too attenuated.²⁶⁷

It was impossible to conclude whether an incompetent individual like Jerry would have consented to the transplant surgery.²⁶⁸ Nonetheless, many courts rely on *Strunk*'s precedent, recognizing the importance of the psychological benefits.²⁶⁹ For instance, the court in *In re Roe* considered the issue of "whether the guardian of a mentally ill person possesses the inherent authority to consent to the forcible administration of antipsychotic medication to his noninstitutionalized ward in the absence of an emergency."²⁷⁰ The court identified six factors as relevant to its determination using the substituted judgment standard.²⁷¹ The third factor the court considered was the impact upon the individual's family:

An individual who is part of a closely knit family would doubtless take into account the impact his acceptance or refusal of treatment would likely have on his family. Such a factor is likewise to be considered in determining the probable wishes of one who is incapable of formulating or expressing them himself. In any choice between proposed treatments which entail grossly different expenditures of time or money by the incompetent's family, it would be appropriate to consider whether a factor in the incompetent's decision would have been the desire to minimize the burden on his family. . . . If an incompetent has enjoyed close family relationships and subsequently is forced to choose between two treatments, one of which will allow him to live at home with his family and the other of which will require the relative isolation of an institution, then the judge must weigh in his determination the affection and assistance offered by the incompetent's family.²⁷²

As *Roe* reveals, while it is extremely difficult "'for the fully competent person to have the sympathetic insight . . . into what it is like' to experience the world with gravely diminished mental function,"²⁷³ "uncertainty about a patient's mental experiences should not lead to their exclusion from the treatment calculation."²⁷⁴

It is important to remember that evidence of psychological benefit does not automatically permit the authorization of a controversial medical

266. *Strunk*, 445 S.W.2d at 148-49.

267. *Id.* at 150 (Steinfeld, J., dissenting).

268. *Id.* at 146; see *supra* note 252 and accompanying text.

269. See *Little v. Little*, 576 S.W.2d 493, 498-500 (Tex. Civ. App. 1979); *Hart v. Brown*, 289 A.2d 386, 390-91 (Conn. Super. Ct. 1972).

270. *In re Roe*, 421 N.E.2d 40, 42 (Mass. 1981).

271. *Id.* at 56-59.

272. *Id.* at 58 (noting, however, that "the judge must be careful to avoid examination of these factors in any manner other than one actually designed and intended to effectuate the incompetent's right to self-determination").

273. CANTOR, *supra* note 72, at 107 (quoting R.S. DOWNIE & K.C. CALMAN, *HEALTHY RESPECT: ETHICS IN HEALTH CARE* 75 (2d ed. 1994)).

274. Dresser, *supra* note 152, at 698.

procedure. The court in *Roe* reminded the parties that “the judge must be careful to avoid examination of the[] factors in any manner other than one actually designed and intended to effectuate the incompetent’s right to self-determination.”²⁷⁵ Thus, courts must balance the benefits and burdens of the procedure and determine whether the treatment produces the greatest total benefit.²⁷⁶

A paradigmatic example of the balancing that courts perform can be found in *In re Storar*, in which the court refused to discontinue blood transfusions for a profoundly incompetent man named John Storar who was afflicted with cancer.²⁷⁷ Storar’s mother refused to consent to the administration of the blood transfusions so a state official petitioned the court for formal permission.²⁷⁸ Experts testified that, without blood transfusions every eight to fifteen days, Storar’s blood would not contain sufficient oxygen to maintain his body, and eventually he would bleed to death.²⁷⁹ With the transfusions, he had energy to engage in regular activities, such as eating, showering, walking, and even running.²⁸⁰

Conflicting expert testimony, however, indicated that the transfusions were merely prolonging his suffering.²⁸¹ The trial court made several findings of fact. First, on a personal level, Storar did not enjoy receiving the treatment.²⁸² The transfusions increased the amount of blood and blood clots in his urine, which made him uncomfortable and confused.²⁸³ Due to his incompetence, he did not understand why he was receiving the treatment, and even resisted forcibly on two occasions.²⁸⁴ Despite his increase in energy, he became more withdrawn—staying in his room more than he did before the treatments began.²⁸⁵ The court also recognized that Storar’s mother was keenly aware of her son’s emotions and had his best interests in mind in making the request to stop treatment:

[H]is mother over his lifetime had come to know and sense his wants and needs and was acutely sensitive to his best interests; that she had provided more love, personal care, and affection for John than any other person or

275. *Roe*, 421 N.E.2d at 58.

276. See *supra* text accompanying note 158.

277. *In re Storar*, 420 N.E.2d 64, 73 (N.Y. 1981), *superceded by statute*, N.Y. SURR. CT. PROC. ACT LAW §§ 1750, 1750-a (McKinney 2003).

278. *Id.* at 66.

279. *Id.* at 69.

280. *Id.*

281. *Id.* at 69–70; *id.* at 78 (Jones, J., dissenting in part) (“[T]he blood forced on him did not serve a curative purpose or offer a reasonable hope of benefit . . .”).

282. According to the majority, “[i]t was conceded that John Storer [sic] found the transfusions disagreeable.” *Id.* at 69.

283. *Id.* The transfusions made urination more painful. *Id.* at 78 (Jones, J., dissenting in part).

284. His resistance was obvious: on one occasion, medical staff had to physically restrain him by tying down his arm to prevent him from pulling out the transfusion needle. *Id.* at 78. To solve this problem, doctors began giving Storar sedatives and pain medication prior to the transfusion. *Id.* at 69.

285. *Id.* at 78 (Jones, J., dissenting in part).

institution, and was closer to feeling what John was feeling than anyone else; that his best interests were of crucial importance to her²⁸⁶

Despite Storar's obvious discomfort and resistance to the treatment, the court concluded that the transfusions should be continued because they were akin to food, were not excessively painful, and helped maintain his regular mental and physical activity.²⁸⁷ Thus, in the court's view, the benefit the treatment brought greatly outweighed the disadvantages of treatment.²⁸⁸ Evidence that his mother in good faith requested the cessation of treatment and that Storar disliked the treatments and became more withdrawn afterward were not sufficient for the majority.

C. Moving Past Psychology: What Else May Be Considered Important to a Profoundly Incompetent Individual?

Strunk and *Storar* demonstrate Professor Dresser's point that courts draw different conclusions from the facts presented based on the judge's notions of morality, reasonability, and the considerations weighed. Determining whether a particular medical treatment is in the incompetent individual's best interests inherently involves a question that is framed by reasonability.²⁸⁹ This objective can easily become obscured.

Dresser proposes that courts "focus more carefully on . . . the interests and pressures that shape actual treatment choices—the patient's current condition, her prognosis, the concerns of those who love and care for her, and the concerns of the larger community to which she belongs."²⁹⁰ Several scholars have similarly advocated for a multidimensional analysis to determine whether a treatment proposal is in the best interests of an incompetent individual.²⁹¹

Examining how a medical procedure will affect other interests besides the person's legal rights ensures that the court is gaining a well-rounded perspective of the individual. Such extrinsic benefits that are unrelated to the medical procedure include the patient's emotional frailty, psychological well-being, social relationship with her family and within its infrastructure, and the social benefit the procedure may provide.²⁹²

Elizabeth Scott has advocated expanding the typical best interests analysis that occurs in sterilization cases to include other extrinsic interests.²⁹³ The "autonomy model," as Professor Scott dubs it, suggests that the analysis should center around three basic inquiries about the incompetent individual: (1) whether the incompetent person has a substantive interest in producing children, or (2) whether there is a

286. *Id.* at 78–79.

287. *Id.* at 69, 73.

288. *Id.* at 73.

289. See CANTOR, *supra* note 72, at 107.

290. Dresser, *supra* note 152, at 616.

291. See Scott, *supra* note 97, at 822–24.

292. See Lewis, *supra* note 130, at 588–90.

293. See generally Scott, *supra* note 97.

substantive interest in avoiding pregnancy, and (3) whether the child is capable of exercising meaningful reproductive choice.²⁹⁴ She then expands the analysis by examining the appropriateness of sterilization as a means of promoting family stability and longevity.²⁹⁵

According to Scott, an incompetent woman may or may not possess a similar substantive interest in procreation or sterilization as compared to a competent woman.²⁹⁶ Traditionally, an individual possesses a substantive interest in producing children if she has the intent and ability to assume a parental capacity.²⁹⁷ To assume a parental capacity, the individual must be capable of performing basic parenting responsibilities.²⁹⁸ This does not mean that the person would make a good parent, she argues, for that would place an unequally high standard of parentability on incompetent individuals and not on competent ones. Rather, the person need only be capable of providing minimally adequate care.²⁹⁹ Under this view, it follows that profoundly incompetent individuals do not have a legally protectable interest in procreation.³⁰⁰ This proposition is supported by state statutes.³⁰¹ If a person lacks a legally protectable interest in procreation, sterilization may be permissible, but that conclusion is not automatic.³⁰² Courts must then examine “nonreproductive considerations such as medical risks and benefits, human dignity, privacy, and family continuity and stability.”³⁰³

Critics of Scott’s model question whether it can adequately protect an incompetent minor’s constitutional interest in procreation. The law recognizes that all persons have a right to make decisions regarding their own reproductive capacities.³⁰⁴ Scott’s model, however, operates under the assumption that only those people who can function as minimally adequate parents retain an interest in procreation.³⁰⁵ This disparate treatment of individuals is criticized as affording individuals different rights based on mental capacity.³⁰⁶ Ultimately, critics argue that a method like this may

294. See Scott, *supra* note 97, at 825–26.

295. See *id.* at 845 (noting how the current model typically ignores the importance of family stability or presupposes that the parents’ request conflicts with the child’s interest).

296. See *id.* at 826–27.

297. See *id.* at 829 (“It is the objective of rearing the child—of establishing a family—that elevates the right to procreate to a lofty status.”).

298. *Id.*

299. *Id.* at 849.

300. *Id.* at 832.

301. Professor Elizabeth Scott cites Montana, Ohio, and Utah as having “laws [that] acknowledge that the incompetent person’s interest in avoiding pregnancy is more important than a theoretical interest in reproduction.” *Id.* at 832–33 & n.88 (citing MONT. CODE ANN. § 72-5-321(2)(c) (2007); OHIO REV. CODE ANN. § 5122.271(c) (LexisNexis 1953); UTAH CODE ANN. § 75-5-321(1)(c) (1993)).

302. *Id.* at 841.

303. *Id.*

304. See *supra* note 116 and accompanying text.

305. See Scott, *supra* note 97, at 849–50.

306. See *supra* Part I.A.1 (describing two divergent theories of personhood).

grant courts too much power over the lives of mentally incompetent children.³⁰⁷

Even Scott concedes that her autonomy model could lead to an unwarranted decision to sterilize, but she proposes several safeguards to protect against this possibility.³⁰⁸ Because Scott's model permits sterilization if review of other extrinsic factors is compelling, there is a concern that parents will make decisions for their children solely based on their convenience, rather than what is in the child's best interests.³⁰⁹ Parents may embellish, even falsify reasons why the treatment is in the child's best interests.³¹⁰ As the Supreme Court has very clearly articulated, "Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves."³¹¹ In order for protections to be adequate, courts should consider parents' interests, but not be persuaded by overstatements.³¹²

III. TOWARD A MORE FLEXIBLE STANDARD FOR THE PROFOUNDLY DISABLED

"Nondisabled Americans do not understand disabled ones," writes Joseph Shapiro.³¹³ In fact, this is the very problem that is inherent within judicial decision making governing the sterilization of profoundly incompetent individuals. The substituted judgment analysis and the best interests test are the two methods that United States courts have designed and currently use as guides for determining whether sterilization is an appropriate procedure to use on profoundly incompetent children.³¹⁴ However, judges are not mind readers. Absent an advance directive,³¹⁵ the substituted judgment test has no relevance.³¹⁶ Thus, judges are left with a best interests test. The best interests test depends upon the judge's ability to extrapolate

307. See *Strunk v. Strunk*, 445 S.W.2d 145, 151 (Ky. 1969) (Steinfeld, J., dissenting).

308. Scott, *supra* note 97, at 852-53. Such safeguards include a comprehensive evaluation of the decision to sterilize by an expert in mental retardation, a mechanism to review the findings of competency, and judicial review or review by a committee modeled after a hospital ethics committee. *Id.*

309. See *id.* at 843 n.128.

310. See John Fletcher, *Human Experimentation: Ethics in the Consent Situation*, 32 LAW & CONTEMP. PROBS. 620, 637 (1967).

311. *Prince v. Massachusetts*, 321 U.S. 158, 170 (1944).

312. See Scott, *supra* note 97, at 855-57. This is especially important when parents request a hysterectomy. In this case, the convenience flowing to the parents from discontinued menstruation may outweigh the benefit to the child or the risk of the procedure. *Id.* at 843, 855.

313. JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT 3 (1993).

314. See *supra* note 119 and accompanying text.

315. See *supra* notes 138-42 and accompanying text.

316. See *supra* notes 143-55 and accompanying text; see also *supra* Part II.A.

the incompetent individual's reality from the evidence presented.³¹⁷ This is an extremely difficult and virtually impossible undertaking given that the evidence in cases involving profoundly incompetent individuals is uncertain and based largely on conjecture.³¹⁸

Even when attempting to compile evidence, courts are unsure of which factors to emphasize. Sterilization cases like *Grady* weigh several factors, with psychological benefit being only one consideration of many.³¹⁹ Courts considering sterilization requests do not weigh psychology as heavily as others,³²⁰ or they may not consider it at all.³²¹ In contrast, nonsterilization cases that have applied the best interests test—such as *Storar* and *Strunk*—have relied heavily upon extrinsic considerations such as the psychological, emotional, or familial benefits that flow from the treatment plan.³²² As a result, judges reach different conclusions because of their different perceptions of the facts.³²³

Part III.A evaluates the substituted judgment and best interest legal tests and commentator proposals presented in Part II and their value as guiding standards for the “Ashley Treatment.” Part III.B proposes that courts perform an intensive factual investigation using available tools and methods of investigation proposed by Professor Dresser. In this investigation, courts may consider extrinsic considerations as well as more objective evidence. Upon examining all the evidence, courts may be permitted to grant a petition to proceed with the “Ashley Treatment” without sacrificing any of the liberties and rights guaranteed by the Constitution.

A. *Evaluating the Application of Current Legal Doctrine to Cases Involving the “Ashley Treatment”*

The *Saikewicz* hybrid decision demonstrates that judges make mistakes in applying these standards.³²⁴ The hybrid model is confusing and illogical when applied to a profoundly incompetent individual.³²⁵ The hybrid analysis also permits courts to support an irrational conclusion by using “evidence” of the preferences and values of an incompetent person when in fact no such evidence exists.³²⁶ Nonetheless, this façade is grounded in the

317. See generally *supra* Part I.B.2.

318. See CANTOR, *supra* note 72, at 106–13.

319. See *supra* note 185 and accompanying text (listing the *Grady* factors); see also *In re Hayes*, 608 P.2d 635, 641–42 (Wash. 1980).

320. See *supra* notes 185–87 and accompanying text.

321. See, e.g., *Hayes*, 608 P.2d at 641–42.

322. See *supra* Part II.B–C; see also notes 237–40 and accompanying text.

323. See *supra* text accompanying note 235.

324. See *supra* note 199 and accompanying text.

325. See CANTOR, *supra* note 72, at 36–37; Pollack, *supra* note 193, at 512.

326. See CANTOR, *supra* note 72, at 37; Dresser, *supra* note 152, at 633; compare *Strunk v. Strunk*, 445 S.W.2d 145, 148 (Ky. 1969) (permitting an incompetent person to donate his kidney to his brother without informed consent because losing the brother would be emotionally harmful to the incompetent person), with *Superintendent of Belchertown v. Saikewicz*, 370 N.E.2d 417, 420–21 (Mass. 1977) (accepting the surrogate's evidence that chemotherapy would cause more harm than benefit to the profoundly disabled patient).

admirable goal of best promoting the interests of the disabled person.³²⁷ By allowing courts to sanction medical procedures that are objectively extreme, this model recognizes that what is extreme for a competent individual may be reasonable for a profoundly incompetent individual.³²⁸ For a court to legally approve of the application of the "Ashley Treatment," there needs to be a flexible, yet constitutional model in place that does not create confusing legal precedent.

Professor Dresser suggests that courts adopt a "revised best interests" test.³²⁹ Her test recognizes that profoundly incompetent individuals inhabit different worlds than competent individuals,³³⁰ but preserves their individual rights guaranteed by the Constitution.³³¹ Dresser's model depends on considering evidence from a variety of sources in order to gain a complete idea of how the incompetent individual exists within his or her world.³³² In this way, the test is more inclusive than the hybrid test, which greatly depends upon the judge's perception.³³³ The revised best interests principle involves a more impartial weighing of interests that will permit judges to approve of new medical treatments, like the "Ashley Treatment."

Similarly, Professor Scott advocates the proposition that profoundly incompetent individuals may not have a similar interest in procreation.³³⁴ This notion, however, is at odds with the guarantees provided in the Constitution.³³⁵ Scott also advances the idea that the preservation of the family is a compelling interest that may be important to a profoundly incompetent child.³³⁶ While this idea departs from a traditional best interests analysis, which takes no account of how a procedure will affect the family, Scott's family-centrism find support in current case law.³³⁷ Nonetheless, without adequate safeguards, courts could begin to authorize procedures that are in the best interests of family members, but not the child whom they are charged with protecting.³³⁸ Therefore, under current standards, parents seeking a court order to perform the "Ashley Treatment" will never meet the stringent burden required—foreclosing it as a viable option.³³⁹

327. See *supra* generally Part II.B.

328. See *supra* notes 254–74 and accompanying text.

329. See *supra* text accompanying note 245.

330. See *supra* notes 246–48 and accompanying text.

331. See *supra* Part I.A.1–3.

332. See *supra* notes 250–51 and accompanying text.

333. See *supra* note 234 and accompanying text.

334. See *supra* text accompanying note 296.

335. See *supra* Part I.A.3.

336. See *supra* note 295 and accompanying text.

337. See *supra* discussion accompanying notes 254–74 (discussing the court's decision in *Strunk*, which recognized the importance of preserving the family sphere).

338. See *supra* text accompanying notes 308–12.

339. See WPAS INVESTIGATIVE REPORT, *supra* note 17, at 15–24.

B. *Classification and Analysis: How Courts Should Consider a Request to Proceed with the "Ashley Treatment"*

Currently, the best interests analysis is the only standard that courts can properly apply when hearing a petition on the "Ashley Treatment."³⁴⁰ Because substituted judgment requires clear and convincing evidence of a prior preference or the establishment of an advance directive, it has no relevance when discussing the "Ashley Treatment," which is a procedure intended for profoundly incompetent children.³⁴¹ Therefore, courts will weigh the pros and cons of the procedure based on the facts presented.³⁴² As the case law demonstrates, facts are presented in many forms depending on who is testifying. For instance, a clinician charged with preserving the medical health of a patient may present a different story of that patient than a family member or nurse who sees the patient interacting on a more regular basis.³⁴³ How the judge chooses to weigh these conflicting stories depends on the judge's moral perspective and what considerations he chooses to weigh more heavily.³⁴⁴ The judge's morality will shape his application of the best interests test so that he applies either a more traditional analysis under *Grady*,³⁴⁵ a hybrid best interests analysis, or an application like Dresser's and Scott's that incorporates many different considerations.³⁴⁶ If the judge concludes that the medical evidence is more powerful than the extrinsic considerations, he may choose to present his conclusion by applying a *Grady* analysis, which only minimally accounts for extrinsic concerns. If, on the other hand, his inquiry reveals compelling extrinsic concerns, the hybrid best interests application will provide a clearer presentation of the evidence.³⁴⁷

This Note proposes that courts should first classify the "Ashley Treatment" as either a reasonable or extreme treatment option based on its potential to greatly improve the child's quality of life. The "Ashley Treatment" is a novel medical procedure.³⁴⁸ To determine whether the "Ashley Treatment" presents a valid treatment option for a profoundly disabled child, it must first pass constitutional muster. By nature, the "Ashley Treatment" implicates fundamental rights that belong exclusively to the profoundly incompetent child.³⁴⁹ As a consequence, the judiciary will police the enforcement of the "Ashley Treatment." Judicial enforcement that is too invasive, however, may infringe upon the

340. See *supra* text accompanying notes 132–42.

341. See generally *supra* Part I.B.1.

342. See generally *supra* Part I.B.2.

343. See *supra* notes 281–86 and accompanying text (describing how the evidence in *In re Storar* was contradictory).

344. See *supra* notes 230–36 and accompanying text.

345. See *supra* notes 174–87 and accompanying text.

346. See *supra* Part II.

347. See *supra* discussion accompanying notes 254–74.

348. WPAS INVESTIGATIVE REPORT, *supra* note 17, at 21.

349. *Id.* at 22; see also *supra* Part I.A.1–3.

constitutionally recognized right of parents to make decisions for their children.³⁵⁰

One way that judges can reconcile the “Ashley Treatment” with existing law is to perform an analysis that determines whether the “Ashley Treatment” is reasonable for the particular profoundly incompetent child. The “Ashley Treatment” by nature is an extreme request because it has the potential to infringe upon a fundamental right or interest. However, based on the particular facts of the case, the request could morph into one that is reasonable. This Note argues that whether the request makes the grand leap from extreme to reasonable is entirely fact specific. *Saikewicz* is a prime example of a case in which the court sanctioned an extreme but reasonable request.³⁵¹ In *Saikewicz*, the court permitted the cessation of chemotherapy, an objectively extreme procedure.³⁵² Under the circumstances, however, the court concluded that withdrawing life-sustaining medical treatment was appropriate and reasonable for *Saikewicz*.³⁵³

The “Ashley Treatment” potentially infringes upon two fundamental interests. First, the treatment involves invading the body of a profoundly incompetent minor without her consent.³⁵⁴ Second, when performed on a young girl, the treatment infringes upon that child’s constitutionally protected right to procreate.³⁵⁵ Society will demand that the courts ensure that these rights are protected vigorously, and will police parental requests that attempt to infringe upon these rights.³⁵⁶ However, this Note proposes that if requesting parents present other compelling *extrinsic* interests that are more important in the particular situation than the fundamental rights which are threatened by the proposed treatment, courts should respect and honor those parents’ requests.³⁵⁷ When courts honor this type of request, they are indicating that the party requesting the treatment presented sufficient factual evidence (clear and convincing) to change the extreme request into a reasonable request.³⁵⁸

Undeniably, parents who request the “Ashley Treatment” will have an uphill struggle to present sufficiently compelling evidence. Currently, parents must present evidence to the court that is “clear and convincing.”³⁵⁹ Courts should not be convinced by unsubstantiated evidence that lacks persuasive value.³⁶⁰ When presented with extrinsic evidence, such as quality of life considerations, psychological and emotional well-being, and

350. See *supra* Part I.A.4.

351. See *supra* discussion accompanying notes 200–22.

352. *Id.*

353. *Id.*

354. See *supra* Part I.A (describing the inherent rights of profoundly incompetent children and the constitutional right to privacy).

355. See *supra* Part I.A.3.

356. See *supra* notes 7, 15–61 and accompanying text (describing Ashley’s case).

357. For a discussion of *Superintendent of Belchertown v. Saikewicz*, which presents an example of a court enforcing this idea, see *supra* Part II.A.

358. See *supra* text accompanying note 248.

359. See *supra* text accompanying notes 150–51.

360. See *supra* text accompanying note 239.

impact on the family structure,³⁶¹ the court should also assess whether the parents are requesting the treatment in good faith or whether the parents are making the request for their own benefit. To do this, courts may use the available tools proposed by Professor Dresser.³⁶² This Note argues that courts should not automatically reject a request to administer the "Ashley Treatment" without performing an intensive factual inquiry into whether the "Ashley Treatment" presents a legally permissible treatment option that is in the best interests of the child.

CONCLUSION

Judge Samuel Steinfeld best articulated the inherent conflict a case like Ashley's presents: "My sympathies and emotions are torn between a compassion to aid an ailing young [person] and a duty to fully protect unfortunate members of society."³⁶³ In an ideal world, the legal standards governing medical interventions would afford mental incompetents infallible protection. Courts have attempted to protect the interests of incompetent minors against involuntary sterilization by creating the substituted judgment and best interests standards. These analyses offer helpful guidelines, but they may be too stringent to permit the authorization of new medical treatments that may bring certain psychological or emotional benefits to profoundly incompetent children. While the "Ashley Treatment" may infringe on important fundamental rights, other interests may surface based on an intensive factual investigation³⁶⁴ that are more compelling based on the particular facts. If the parents have presented sufficient clear and convincing evidence before a court showing that administering the "Ashley Treatment" is more important to the child than her fundamental interest in procreation and bodily integrity, then the request is extreme, but nonetheless reasonable, and courts should carefully examine whether the procedure is permissible in the particular case.

361. See, e.g., *Saikewicz*, 370 N.E.2d 417. For a discussion of *In re Storar* and the psychological and physical consequences of treating Storar with a blood transfusion, see *supra* notes 277-86. See also Lewis, *supra* note 130, at 588-94.

362. See generally *supra* notes 250-53 and accompanying text.

363. *Strunk v. Strunk*, 445 S.W.2d 145, 149 (Ky. 1969) (Steinfeld, J., dissenting).

364. See generally *supra* Part II.B-C.